

Thursday, May 11

09:45 - 11:05 - Health I - Mental health, psychosocial and physical wellbeing Hilton Nordica - Meeting Room G /

Neurobehavioral Assessment of Youth Trauma: A Means of Preserving the Calm to Prevent a Storm.

Ann Marie Leonard-Zabel,

Curry College, Sandwich, Massachusetts 02563, United States

Neurobehavioral Assessment of Youth Trauma: A Means of Preserving the Calm to Prevent a Storm.

By: Dr. Ann Marie Leonard-Zabel, Massachusetts, USA.

Trauma, especially among learning disabled youth, is more prevalent since the impact of COVID-19 and its variants. Trauma Brain Processing will be explored to understand youth trauma impact involving four (4) areas: (1) How the brain scans and senses a real or perceived threat, (2) when a threat is perceived how does the brain systems become hijacked and send an alarm system of threat, (3) how one reacts to the flight, fright and freeze response of coping, and (4) how prior childhood trauma can increase the brain-body responses resulting in possible numbing and/or psychosocial dissociation. The developing brain on stress will be examined from an allostasis and epigenetics impact on body health and wellness.

As a means of neurodevelopmental consequences impacting neuropsychological implications of traumatic stress, an assessment of attention and executive functioning, visuospatial, language, and memory systems, along with motor and psychomotor speed, may prove beneficial with inducing calm and preventing a storm of anxiety, depression, and mood disorder(s) to escalate. From the findings, the use of evidence and culture-based mental health interventions can be employed worldwide such as psychological first aid, psychological debriefing, cognitive behavioral therapy, narrative treatment and emotional disclosure, and school-based interventions, among others.

Resources to assist with addressing trauma will be explored to include evidenced-based trauma informed schools, learning policy initiatives involving trauma-sensitive schools via a descriptive study, and resources addressing COVID-19 impact for age-related reactions to a trauma. Further review of trauma involving the DSM-5/DSM-5 TR, the World Health Organization, and Resilience Resources will be provided. Overall, the variety of approaches and resources can be utilized to treat youth trauma and bring clam rather than a storm of despair. Thank you.

Disabled students' educational and psycho-social experiences during the COVID-19 pandemic crisis

Anastasia Vlachou¹, Stavroula Kalaitzi², Anastasia Toulia³, Filippos Papazis¹,
Theodora Papazoglou¹, Aristeia Fyssa⁴, Lia Tsermidou⁵

¹ *National and Kapodistrian University of Athens, Athens, Greece*

² *National and Kapodistrian University, Athens, Greece*

³ *University Of Thessaly, Volos, Greece*

⁴ *University of Patras, Patra, Greece*

⁵ *National and kapodistrian University of Athens, Athens, Greece*

The COVID-19 outbreak has high and virtually deleterious effects on all aspects of disabled pupils' lives, affecting also their developmental progress, school learning and wellbeing. Due to the pandemic sealing off, and other social distancing measures, disabled learners faced significant challenges amplifying their ongoing segregation and discrimination from educational structures and services. In the light of the above, this study aims to explore the lived experiences of primary and secondary school-aged disabled students as they are transitioning from quarantine and distance education back to their schools during the pandemic crisis. In particular, this qualitative study aims at addressing disabled students' voices through the use of semi-structured interviews about the impact of COVID-19 policy decisions in Greece on their educational life, psychology, and social relationships with others. The analysis unfolds around five main thematic axes: 1) educational experience(s) during the implementation of remote learning (accessibility, structure and organization of learning), 2) challenges (educational domain, social domain, lack of services and accommodations, specific needs related to remote learning, changes in everyday life), 3) positive experiences during the implementation of remote learning, 4) support (educational, psycho-social), and 5) returning to school-emerging from lockdown (educational support, psycho-social support). In most cases of students there was an evident absence of psychological support offered to them while those who attended general schools highlighted, the inability of their special education teachers to adopt their role and offer support to the remote learning. The results are discussed in terms of processes and birer towards the creation of more inclusive educational communities

Mental health and resources of parents of children with a recent diagnosis of disability: self-compassion and support received

Monika Skura,

University of Warsaw , Warsaw, Poland

Experiencing chronic psychological stress negatively affects the quality of the relationship with the child and the ability to care for the child. Self-compassion is being open and sensitive to one's own suffering while experiencing feelings of care and kindness towards oneself. It is worth examining whether self-compassion for among parents of children with a recent disability diagnosis affects their mental health or the stress they experience Social support may play an indirect role in the relationship between stress and an individual's psychological functioning. We also wanted to find out whether the support received influences better functioning of parents of children with a recent disability diagnosis in terms of their mental health and perceived stress.

The study aimed to find out whether the level of perceived general stress and the level of experienced parental stress, self-compassion and received support differ according to the type of disability of their children.

Quantitative methodology using parametric questionnaires: PSS-10 (Perceived Stress Scale), SCS (Self-Compassion Scale), GHQ-28 (General Health Questionnaire); PSI-4-SF (Parenting Stress Index); MSPSS Multidimensional Scale of Perceived Social Support). The research will be conducted with respect for ethical principles.

Criterion: 1) parents of children from four groups (autism spectrum, delayed cognitive development); 2) parents of children aged 0 to 7 years old

There are differences in self-compassion between the groups, which affects the mental health of individual parents, which in turn indicates which parents need more support. The highest levels of stress are experienced by parents of children on the autism spectrum, but these parents also have ready access to a large network of support. For an invisible difficulty such as that of intellectual disabilities, the situation is different. Parents receive more support the more visible their child's disability is.

A systematic review on Mental health among people who use AAC

Jørn Østvik¹, Mats Granlund², Astrid Røsland Seim¹,

¹ *Norwegian University of Science and Technology (NTNU), Trondheim, Norway*

² *Jönköping University / NTNU, Jönköping, Sweden*

In general, mental health issues among the general population are frequent topics among researchers. In the research literature, a number of researchers have reported mental health among people with disabilities in general. However, attention is rarely paid to mental health among people who use augmentative and/or alternative communication (AAC). Based on a dual model of mental health and mental health problems, researchers have made a dual distinction between the concepts of mental health, and of mental health problems.

This presentation reports preliminary findings from a systematic literature review investigating current knowledge about mental health and mental health problems among children, adolescents, and adults who use AAC. The theoretical foundation for the present study is based upon this dual model. The review has the following research questions: 1) What characterizes mental health and mental health problems among people who use AAC?, and 2) What factors are reported to impact mental health among people who use AAC? People who use AAC is a population with great diversity in terms of the cause of communicative constraints, the need for communicative support, and the opportunities to develop functional communication. In previous research, people who use AAC are reported to be subject to exclusionary practices in the community, to have few close social relationships and friendships, and being in risk of perceiving loneliness.

Literature search was conducted in a total of 21 literature databases by using search terms in English, Norwegian, Swedish, and Danish respectively. Inclusion criteria were people who use all types of unaided and aided communication, and who use AAC as the main communication form in a longer time perspective. Mental health problems can be self-reported or diagnosed. The included publications were empirical studies reported in peer-reviewed articles, doctoral dissertations, or master theses. Major findings from the review are presented and shortly discussed.

Web-based training intervention to increase physical activity level and improve health for adults with intellectual disability

Sanna Fjellström¹, Marie Ohlsson¹, Elisabeth Hansen¹, Anna Nordström¹, Eva Flygare-Wallén², Mats Jong¹, Jessica Holttö¹, Magnus Zingmark²

¹ *Mid Sweden University, Östersund, Sweden*

² *Municipality of Östersund, Östersund, Sweden*

Individuals with intellectual disability (ID) are less physically active than people without ID, and rarely or never reach the recommended daily dose of physical activity level. Individuals with ID have a higher BMI than individuals without ID, and therefore a higher risk of cardiovascular diseases. The overall objective was to determine the effectiveness and user experience of a 12-week, web-based training program, customized for people with ID.

Participants with ID living in communal settings (n=27, 48% female, age = 36.4±9.56 years) were recruited for a training study including 50 minutes training 3 times a week in 12 weeks. Staff working with the participants (n=8, 62% female) were recruited for interviews. Qualitative and quantitative measurements was used pre- and post-training period. Questionnaires were used to evaluate enjoyment, quality of life and physical activity level, along with interviews. Body composition was measured as well as waist circumference.

This study showed that 85% of the participants completed the web-based training. The level of physical activity increased and positive changes in health outcomes were observed, for example a decrease in fat mass by a mean of 1.9kg ±2.4. The study also high-lighted barriers and facilitators for people with ID to use web-based training, along with perspectives and experiences on health and exercise among the staff within the supported housings.

A web-based training program is a new way to increase level of physical activity level for people with ID. This study showed that web-based training program is an effective tool to improve health parameters, reduces hinders such as transport. Moreover, it is an easy way for staff to enhance physical activity in their work. The study was performed during the Covid-19 pandemic, which might have influenced the interest of the study in a positive manner.

11-05-2023

09:45 - 11:05 - **Services I - Management of services** Grand Hotel -
Huginn /

Performance Measurement - Measuring for Governance or Quality

Rebekka Bruteig, Jan Tøssebro, Odd Morten Mjøen

NTNU Social Research, Trondheim, Norway

The background for the presentation is an increasing importance of performance measurement as a tool for quality improvement and management in Norwegian health and care services. On the national level, the Norwegian Directorate of Health have developed national health care quality indicators that municipalities are recommended to use to measure quality and is argued to contribute to quality improvement and transparency. There also are reservations about the indicators, such as they reflect quality to a limited degree and that there is a need for more outcome indicators.

The aim is to present how quality improvement of health and care services is done at a local level, as the municipalities have a certain autonomy when it comes to *how* they govern and improve quality.

Method: Interviews with top and middle managers in services for people with intellectual disabilities and mental health difficulties, home care services and nursing homes.

The overall picture is that managers have different motivations for using performance measurements, such as transparency, to compare services and improving service quality. Differences in motivation are seen between top and middle managers and somewhat between the different types of services. Measurements are chosen based on what is available in administrative system, an argument being that it shouldn't take extra resources to create them. Thus, most indicators are input og process indicators, mainly used for governance purposes. The impact of measurements on the services are unclear, but we can see that they are used for finding cost-cutting possibilities, as a defence against critique and that there is a risk of routinization of services because of reporting.

The impact of quality measurement is ambiguous. It is a tool for governance and on the other side managers wish for better measurements of user outcome, to capture *quality* in a better way.

Exploring the factors that impact on the development of community-based services in the Czech Republic: stakeholders' perspective

Kristýna Janyšková¹, Šárka Káňová¹, Karel Řezáč¹, Julie Beadle Brown²

¹ *University of West Bohemia, School of Education, Pilsen, Czech Republic*

² *University of Kent, Canterbury, United Kingdom*

The aim of this paper, which was implemented as a part of a larger 3-year project, was to explore some of the factors that impact on the development, nature and quality of community-based services in the Czech Republic.

Semi-structured interviews were conducted with senior managers of 16 community-based services, representatives of Disabled People's Organisations, parents of people with intellectual and developmental disabilities and deputies of local and regional authorities, across the three regions of the Czech Republic.

There is still a gap in understanding what the quality of support is and how to measure it. Despite the support from authorities and/or the European Funds, service providers are still afraid of Deinstitutionalisation.

Implications for the further development of community-based services, including ensuring people with more complex needs will be discussed. This project has been financially supported by the Czech Research Foundation (project no. 20-08327Y).

Training in active support and its impact on community-based services in the Czech Republic: a small-scale clustered randomized control study

Šárka Káňová¹, Kristýna Janyšková¹, Karel Řezáč¹, Julie Beadle - Brown²

¹ *University of West Bohemia, School of Education, Pilsen, Czech Republic*

² *University of Kent, Canterbury, United Kingdom*

The quality of life of people with intellectual and developmental disabilities in community-based services is connected with quality of the support provided. This paper presents findings from a small-scale clustered randomised control study of Active support, supported by the Czech Research Foundation (project no. 20-08327Y).

Structured observations were used to collect baseline data in 16 services on the levels of engagement in meaningful activities and relationships, the quality of support, and whether staff were receiving practice leadership. Training on active support was then provided in 8 services, randomly allocated to the training or the wait list control condition. Final structured observation was then implemented to assess outcomes from units which underwent the training and those in control group.

Baseline data indicated that those supported by community-based services had in average lower levels of support needs in comparison to previous studies, while average levels of engagement and the quality of support were higher than normally found in such studies. However, there was substantial variability. Findings from both structured observations will be presented.

This is the first time such study has been conducted outside the USA, Australia or the UK and in a country that is at a much earlier stage of de-institutionalisation. The implications of the findings for wider implementation will be discussed.

Welfare by counting? The making of "quality" into a quantifiable policy within public health care services

Gunhild Tøndel, Jan Tøssebro, Odd Morten Mjølten

NTNU, Trondheim, Norway

The term “quality” has become an important policy driver within public health and care services. Quality is often measured quantitatively, for instance through quality indicators. This little example expresses a cultural tendency towards quantification that during especially the past thirty years has become a characterization of modern society (e.g. Mennicken and Espeland, 2019). In organizations, this is visible through the structuring of their activity around performance measures, cost-benefit analyses, risk calculations, ratings and rankings. Welfare state services are no exception and necessitates studies of the co-constructive relationship between policy development and tools of knowing the governed.

This paper studies the making of quality into a quantifiable policy through tracing the making of a national system for quality measurement in Norwegian municipal health and care services. The data material is primarily policy documents covering the period from 1990-2022, such as official governmental papers, but also organizational/technical papers that describe system development. The documents are complemented with qualitative interviews with key policy actors within this sector. The data is an empirical lens into the emergence and institutionalization of this specific way of knowing “quality” within health and care policy. Three analytical levels are treated: national policy, local development and policy, and activities operating in the in-between shades. The paper addresses different services, such as nursing homes, home-based care services, and group homes for intellectually disabled people and people with mental health problems. Among other findings, the paper describes two relatively clear turning points in the trajectory of policy; around 2000 and 2011, with a shift in focus from a typical socio-political reasoning to the quality of care and an introduction of a more facts-based approach to quality. The paper does not call for eliminating quantitative indicator policy, but to explore the knowledge that is part of decision making in this field.

11-05-2023

09:45 - 11:05 - **Human rights I - Disability human rights** Grand Hotel - Hvammur /

- Moderator: Rannveig Traustadóttir, University of Iceland
- Moderator: Inger Marie Lid, VID Specialized University

The Emerging Field of Disability Human Rights

Inger Marie Lid ², Rannveig Traustadóttir¹

¹ *University of Iceland, Reykjavík, Iceland*

² *VID Specialised University, Oslo, Norway*

This paper introduces the emergence of a new interdisciplinary field: *Disability Human Rights* and the two NNDR conference sessions on this topic. Disability Human Rights combines disability studies and human rights law in addressing the lives and experiences of disabled people. The Convention on the Rights of Persons with Disabilities (CRPD) ushered in a new era of disability research – one that is not focused just on law or on social science.

Instead, the CRPD has provided a new framework for researchers to engage in disability inquiry that necessitates engagement across a range of disciplines. Disability Human Rights brings together the previously disparate fields of disability studies and disability rights and provides a platform for interdisciplinary collaboration towards disability justice goals. This paper will discuss the reasons for the emergence of this new interdisciplinary field, propose a definition of Disability Human Rights, and reflect on its impact within different areas of inquiry, on social justice research, and disabled people's lives.

The papers presented in the two conference sessions on Disability Human Rights will also contribute to an upcoming Special Collection of the SJDR (Scandinavian Journal on Disability Research) celebrating this emerging field. The conference sessions on *Disability Human Rights* also celebrate the 15th Anniversary of the entry into force of the CRPD in May 2008.

Inclusion in Times of Triage

Theresia Degener,

Protestant University of Applied Studies, Freiburg, Germany

On 8th December 2022 the German parliament adopted a triage law which regulates the procedure to be followed in German hospitals in case of shortage of medical resources due to the Corona pandemic which leads to the question of 'whose life to save'. The German triage law substitute former guidelines issued by the German Interdisciplinary Association for Intensive and Emergency Medicine (DIVI) on ethical decisions on the allocation of resources in emergency and intensive care medicine in the context of the COVID-19 pandemic published in March 2020. Nine disabled activists filed a constitutional complaint at the Federal Constitutional Court of Germany against these recommendations, arguing they violate the human rights in the German Constitution, namely the respect for and protection of human dignity, as well as the prohibition of discrimination. They demanded the German legislator to take action as required by the principle of subjection to the law, one of the essential principles of the rule of law. Essential measures relevant to the fundamental rights of our society must be regulated by the legislature itself. The Federal Constitutional Court of Germany agreed. In an order of 16 December 2021 it held that in view of the German Constitution and in view of the Convention on the Rights of Persons with Disabilities (CRPD), it is incumbent upon the legislator to take sufficiently effective measures preventing any discrimination on the basis of disability in the allocation of scarce intensive care resources in the event of pandemic-related shortages. The now adopted triage law entails a non-discrimination provision related to disability, the degree of frailty, age, ethnic origin, religion or belief, gender or sexual orientation. Triage decisions may only be made on the basis of the current and short-term likelihood of survival of the patients concerned. Despite this non-discrimination provision, the German triage law discriminates against disabled and elderly patients because it does not protect against indirect and structural discrimination in the German health care system as it relates to pandemic situations. It is based on the medical model of disability and devalues the human rights model of disability. The article will analyse the German triage law from a CRPD angle. It will further give an overview over the triage debate in Germany. It was ignited by the disability rights movement via strategic litigation with ephemeral victories in front of the Federal Constitutional Court but with harsh losses in the parliamentary and media debates. The long shadows of the past caught up with the disability rights movement.

The Role of Rights Protection Officers in Enabling Effective Access to Justice for Disabled Women in Iceland

Eliona Gjecaĵ,

University of Iceland, Reykjavík, Iceland

Access to justice enables people to have their voices heard and to exercise their legal rights enshrined in national legislation and international human rights conventions. As critically important as this is, there is still little knowledge, understanding and research focusing on access to justice for disabled women in connection with the reporting, investigation and prosecution processes of gender-based violence against them, internationally and in Iceland, where the research reported here was conducted. This interdisciplinary research employs a human rights approach in combining disability studies, gender studies and disability law and policy to gain a comprehensive and holistic view of this topic. Qualitative methods have been used to gather data on the lived experience of disabled women who had been subjected to violence, and the experience of people who had supported them through the justice system (for example, with reporting the violence and associated investigation and prosecution processes). Semi-structured interviews were carried out with three types of participant: A) 16 interviews with self-identified disabled women with a range of different impairments (including physical, sensory and intellectual), age, gender identity, ethnic background, education, and socio-economic status; B) 15 interviews with professionals working in support frameworks focusing on disabled women who have been subject to violence; and individuals working within the justice system in connection with reporting and prosecution (e.g. rights protection officers, lawyers, police, prosecutors, judges).; and C) five interviews with experts in the field of disability and violence. Analysis of court documents, national laws, policies, and international human rights treaties was also conducted. This article focusses on the role of Rights Protection Officers (RPOs) and identifies it as a procedural accommodation required by Article 13 of the UN Convention on the Rights of Persons with Disabilities (CRPD) that enhances effective access to justice for disabled women when detecting, reporting and prosecuting the gender-based violence that they were subjected to. It draws from qualitative interview data with disabled women, RPOs, professionals working within the justice system, and experts in the disability field and justice system. It furthermore draws on human rights law and Icelandic legislation and criminal procedures, to analyse the importance of such role in supporting women their right to access the justice. The findings describe and discuss the role of RPOs regarding access to justice for disabled women, as well as the limitations to their role. This also includes highlighting RPO's helpful role in the overall proceedings in informing other justice workers in how to facilitate and accommodate disabled women who report violence. To this end, the article argues that the provision of RPOs should be legitimized as part of enabling effective access to justice for disabled women and their role be strengthened.

Independent but alone? A story of discrimination and ableism within the Icelandic child protection system.

Ágúst Fannar Leifsson¹, Hanna Björg Sigurjónsdóttir², James G. Rice³,

¹ *Parent, Reykjavík, Iceland*

² *University of Iceland, Reykjavík, Iceland*

³ *University of Iceland, Reykjavík, Iceland*

This contribution presents the co-authored story of a young father with intellectual and developmental disabilities who recently had his daughter removed from his care after an extensive fight through the Icelandic court system. His story illustrates how he and his family were systematically discriminated against within the child protection system, demonstrating the ableist views of a system that understands disability only as a risk to the welfare of children. The narrative will detail a number of issues, such as a lack of knowledge on the system's part as to what disability means and how parents with disabilities need to be supported, combined with a heavily psychologically based assessment system which focuses on individual deficiencies while ignoring parenting strengths. What is particularly troubling in this case was the insistence that the father needed to reside alone with his child 'independently' as evidence of his parenting capacity. This ignores the interdependent nature of what parenting entails in practice. Further, instead of seeing the extended family as a resource or a strength, this supposed 'dependency' was interpreted as a sign of the father's childlike status as someone in need in care not as a care provider himself. This reflects some long-standing cultural stigmas about people with intellectual disabilities, but also misrepresents the notion of 'independence' which underpins the ideology of some key aspects of the disability rights movements. Most of these issues are not new. However, the fact that these forms of discrimination persist within an ostensibly changed human rights environment, informed and supported by the CRPD, suggests that these stories still need to be told as well as analysed within the changing disability rights environment.

11-05-2023

09:45 - 11:05 - **Inclusion II - Inclusive Research with People with intellectual and Developmental Disability** Grand Hotel - Útgarður /

- Moderator: Esther Murphy, Trinity College Dublin

Co-design of tools for budget planning and time management together with people with ID

Stefan Johansson,

Begripsam and KTH, Royal Institute of Technology, Stockholm, Sweden

The project "My Adult Life" aims to prepare young people with ID to take the step to leave school and enter the life as adults. Among everything you need to know, time management and economy constitutes basic skills that everyone need. This was decided by the students with ID as the most important areas to have a digital tool as support.

Students with ID in schools around Sweden have worked together with Designers, Accessibility Experts, Teachers, and Researchers in Special Education to co-design two digital tools. The tools are designed with Universal Design in mind and to comply with the ISO standard 21 810-1 for Cognitive Accessibility.

In this session we will present the tools: The Budget Board and My Time Planner and share some insights from how people with ID can take part in a design process and heavily influence the outcome.

DigiAcademy an accessible digital skills education programme co designed with and for people with intellectual disabilities: Sharing our Citizen Advisory Panel team members' experiences

Esther Murphy, Sara Fiori, Orla Shiels, Amy Fulcher, Brian Hogan, Christina Burke, Cormac Hanley, Darren Heduan, Denise Breslin, Fionn Crombie Angus, Ifiok Umo, James Delaney, Joe McNamara, Lia Gogarty, Linda Byrne Duffy, Mei Lin Yap, Sarah Boyne

Trinity College Dublin, Dublin, Ireland

Research provides evidence that people with intellectual disabilities (ID), are being left behind in a time during the pandemic which requires more than ever their full participation in our digital society. Health and education professionals, carers and families face challenges to support health and inclusion needs. The need for accessible digital skills training to empower people with ID to manage their health, wellbeing and social inclusion has been identified. Digi-ID PLUS is a multidisciplinary European partnership with disability organizations, advocacy groups, education, engineering, health academics and practitioners addressing this challenge of digital inclusion and digital literacy among people with ID. DigiAcademy is an accessible digital skills e-learning platform co-designed with and for people with accessibility needs to address this challenge. Included within the team is our Citizen Advisory Panel (CAP), fourteen individuals with ID, hired as digital inclusion experts by experience based in lead Partner country Ireland. The Panels have intentionally been designed to include diverse voices with diverse age, gender and digital competency to learn from their lived experiences and ensure their voices shape every key project decision.

In our paper we will present experiences of our citizen advisory panel from Ireland focusing on insights from all the members and their role in our inclusive co-creation process validating and reviewing our DigiAcademy app. We will also present our citizen advisory panel teacher training methods and peer mentoring model established to enhance engagement and digital skills acquisition.

Inclusive participatory research: a guidebook for researchers and clinicians who benefit from the presence of collaborators with experiential knowledge

Marie-Hélène Poulin¹, Marie-Hélène Morin², Marjorie Desormeaux-Moreau³, Lucila Guerrero⁴, Marie Grandisson⁵, Claude Normand⁶, Suzie McKinnon⁷, Mélanie Couture³, Gabriel Normandeau¹

¹ *Université du Québec en Abitibi-Témiscamingue, Val-D'or, Canada*

² *Université du Québec à Rimouski, Rimouski, Canada*

³ *Université de Sherbrooke, Sherbrooke, Canada*

⁴ *Centre Hospitalier Universitaire Sainte-Justine, Montréal, Canada*

⁵ *Université Laval, Québec, Canada*

⁶ *Université du Québec en Outaouais, Gatineau, Canada*

⁷ *CIUSSS Saguenay-Lac St-Jean, Sept-îles, Canada*

As part of a research project aiming to link health with social services programs for people with autism who request mental health or addiction services, researchers and clinicians are being called upon to collaborate with people who have experiential knowledge related to their diagnosis of autism. In order to promote the well-being of people with autism who participate in working committees, a guidebook on inclusive participatory research has been developed and training will be provided to all research committee members in relation to these contents. This guidebook is divided into two sections: the conditions necessary for collaborative work and ways to integrate these conditions into the research process. The main themes that structure this guidebook are 1) valuing experiential knowledge, 2) providing clear and mutually acceptable guidelines, 3) accepting flexibility and openness, and 4) making a commitment to professional development and training. This guidebook will be available in several formats (black and white, color, with several images, in Easy Read format, in Word, etc.). Modifiable collaborative tools are offered on a web platform for easy access and use. This guidebook was developed in partnership with researchers from different disciplines, clinicians, people with autism and students. Its content will be presented and its applications in research will be discussed.

“That makes sense” Generating ideas, disseminating findings and editing research together: Reflections on research activities conducted inclusively with people with intellectual and developmental disabilities.

Darren Chadwick¹, Vince Peters², Cameron Richards², Sarah Offley²

¹ *Liverpool John Moores University, Liverpool, United Kingdom*

² *Dudley Voices for Choice & The West Midlands Self Advocacy Network, Dudley, United Kingdom*

Background: Inclusive research practices with people with intellectual disabilities and autism, though still relatively rare in research pertaining to these groups, has gained a critical mass of acceptance, activity and guidance over the past two decades. It now is embedded via patient and public involvement initiatives in many calls for research but is still distinct from consultative work and does not generally mirror research practices conducted with the general population. Nonetheless, it is an approach that is constantly developing and evolving presenting both challenges and benefits to the research endeavour.

Approach: This study utilises autoethnography and a reflexive case series to provide insights into including co-researchers with intellectual disabilities, autism and ADHD in research endeavours including discussing and deciding on research focus and design, developing easy read reports of research findings and editing a journal special issue. From reflexive journals, diaries and conversations with co-researchers, insights into the facilitators, barriers and outcomes of these endeavours for the co-researchers with and without disabilities are explored. These data were analysed using constructivist qualitative analysis to discern meanings for each of the parties in engaging with these inclusive research activities. **Findings:** Challenges centred around time limitations and deadlines, clear accessible communication of goals and activities by the co-researcher without disabilities and marrying individual and wider group comprehension priorities in dissemination. Benefits for the co-researchers with intellectual disabilities included a sense of occupation and skill development, having their contribution acknowledged and valued, and financial remuneration. Beneficial for the co-researcher without intellectual disabilities was enhanced intrinsic motivation and a greater sense of the worth of the research activities undertaken.

Conclusions: For the parties involved inclusive research practices provided a great deal of value and benefit, though management of challenges relating to time, financial remuneration and communication are useful to consider for those undertaking such pursuits

Methodological considerations and adaptations of focus group-discussions with and for people with cognitive and intellectual disabilities

Kristin Alfredsson Ågren, H. Lindström , D. Michailakis

Linköping University, Norrköping, Sweden

Young adults with intellectual disability (ID) and cognitive difficulties with an interest in online gaming were participating in a research project on adapted employment. Most of the participants were not having employment or everyday occupations outside their home and most experienced limited social connections outside their online communities.

The aim with this presentation is to describe methodological considerations and adaptations to enable inclusion in focus groups of young adults with intellectual disabilities (ID) and cognitive difficulties with an interest in online gaming, to explore the influence of their online gaming on everyday life activities and on adapted employment from their own perspective.

Methodological considerations were identified and decided upon together. Various adaptations and tools were used during the data collection to meet different needs of cognitive adaptations. They were developed within the group of participants and researchers, and with input from an expertise group of staff and interest organisations.

Experiences show that it was described as important to have met the researchers digitally or physically before the focus group took place. Reminders were identified as needed prior to the focus group. Cognitive adaptations to be used to implement the focus group discussions were developed together. Choices of how to conduct the focus groups were needed, as well as alternatives.

To conclude, aspects of adapted employment can be explored from the perspective of participants with ID and cognitive difficulties with an interest in online gaming using physical or digital focus group discussions. Different methodological adaptations and careful planning of the implementation process were needed in cooperation with participants. Both Pros and Cons with the used adaptations and the considerations made are discussed

11-05-2023

09:45 - 11:05 - **Inclusion I - Gender 1** Grand Hotel - Ásgarður /**Special education systems making (m)others 'mad': Madness as a discourse of social control**Katherine Runswick-Cole², Patricia Douglas¹, Penny Fogg²¹ *Brandon University, Brandon, Canada*² *University of Sheffield, Sheffield, United Kingdom*

This paper investigates discourses of (m)othering and madness and social control in global North special education systems. We use the term (m)others to pay attention to the continued impact of the gendered nature of care for (disabled) children at the level of the individual, but also to recognise gender as a social construct, and the many ways of being a (m)other (Anderson). We draw on a thematic analysis of focus group discussions with (m)others of disabled children in South Yorkshire, United Kingdom and Ontario, Canada who came together to discuss their experiences of parenting children in special education systems, paying close attention to what we describe as 'intimate encounters' between (m)others and practitioners that occur day-to-day in (special) education settings. The developing analysis is shaped by critical disability studies and an engagement with the academic literature that explores gaslighting from psychological and sociological perspectives (Kline). We also perform a reading, alongside the themes from our focus group, of the play *Gaslight* (Hamilton). We argue that the concept of 'gaslighting' offers a useful framework both for understanding 'intimate encounters' between (m)others and practitioners and for challenging the operations of power in special education systems. Our broad aim is to expose the ways in which special education systems across the global North are constructed in ways that make (m)others of disabled children 'mad'. We conclude by reflecting on what new understandings of intimate encounters between (m)others and practitioners have been revealed and how they have the potential to (re)shape practice.

Anderson, K. L. (2005). Theorizing gender in intimate partner violence research. *Sex Roles*, 52 (11-12), 853–65.

Hamilton, P. (1938). *Gaslight*. Samuel French.

Kline, N. (2006). Revisiting once upon a time. *American Journal of Psychiatry*, 163(7), 1147–1148.

Making Madness: Mothers' experience of advocacy in the educational context.Penny Fogg¹, Katherine Runswick-Cole², Patty Douglas³¹ *School of Education, University of Sheffield, Hebden Bridge, United Kingdom*² *School of Education, University of Sheffield, Sheffield, United Kingdom*³ *Brandon university, Manitoba, Brandon, Canada*

We are a group of mothers, academics and practitioners based in Yorkshire (UK) and Toronto (Canada). we have used story-telling methods to help us understand the experience of mothers who advocate for their disabled children in educational contexts.

Mothers of children with disability lose trust in systems and practitioners when they discover that their children's right to education is conditional, and their inclusion precarious. Through advocacy they are drawn into an unusually close relationship with institutional power. Despite being positioned as partners in their children's education, structural aspects of service delivery and culturally available discourses of patriarchy and ableism complicate and toxify the relationship between power and knowledge in this situation. Through engagement with systems and practitioners mothers are subject to unusual levels of exposure and evaluation. They can easily lose confidence in their own judgement. The fragile dialogical space in which assessments and meetings take place can quickly become adversarial. Caught in this unequal territory it can be risky for mothers to advocate strongly, as strong advocacy can invoke ableist and patriarchal institutional defences, positioning them as 'difficult, pushy, vulnerable, or mad'.

Mothers in our study also told stories of good practice: restorative encounters of allyship, with practitioners, and other mothers, but such 'micro-kindnesses were inconsistent and unreliable, and for some, extremely rare. Instead, the stressful experience of advocacy, extending over decades, was exhausting and de-stabilizing.

We propose this experience needs to be understood within a broader cultural lens- of trauma and discrimination. We acknowledge the importance of articulating moments of recognition, respect and understanding as a form of anti-discriminatory practice. Prior to this however, systems and practitioners need to understand and acknowledge how mothers are made 'mad' by processes of discrimination which are present in the systems intended to support them, and their children.

Strategies of Vulnerability? (De)Politicisation and Russian Disability Organising

Philippa Mullins,

American University of Armenia, Yerevan, Armenia

This paper explores Russian civil society organising around disability. Drawing on in-depth interviews with civil society actors conducted 2017-2018, the paper analyses (a) how legitimacy is constructed through apparent depoliticization and (b) the opportunities and threats of this strategy for disability organising.

To illustrate the tension of depoliticisation as strategy, I look at the experiences of LGBTQ+ disabled people. While LGBTQ+ identities are normatively politicized, disability identities are normatively depoliticized. The apparent compliance of disability organizing with legitimacy norms for civil society actors may create a space where LGBTQ+ people feel required to erase or obscure their sexuality and/or gender identity. Remaining legitimised as a civil society actor thus requires perpetuating the misrecognition of disability, by distancing from association with sexual and gender identities which fall outside dominantly translated norms about disability. These aspects of identity are in tension with reductive - but legitimised - religious, charitable, and passive images of disabled people, as well as being associated with delegitimised areas for civil society organising.

I thus argue that legitimization as a civil society actor is contingent on perpetuating the misrecognition of disabled people as non-agentic, passive, and desexualized. I demonstrate

how apparent compliance may structure unequal recognition and exclusions – essentializing the very vulnerability which may be strategically used to resist. This raises questions about how disability civil society organisations enact, negotiate, and instrumentalise legitimacy, as well as about the tensions for representation and change present in strategic uses of vulnerability.

Storying ableism: Proposing a feminist intersectional approach to linking theory and digital activism

Rahel More,

University of Klagenfurt, Klagenfurt, Austria

Storying is a way of understanding the world and deeply embedded in the existence of stories and storying there is theory. Digital feminist disability activism addressing ableism offers stories on what it means to be human, and their storying is a way of understanding and theorizing the world. The concept of ableism originates from the disability rights movement and Disability Studies, an academic field closely linked to disability activism. Ableism theory refers to a human corporeal norm reinforced by the dis/ability binary and the structural and relational de/valuing of abilities. Despite its intersectionality, ableism is often reduced to the binary opposition of disabled/abled. Ableism however shifts the focus from disability to processes of abledment (formations of abledness). Relations of the norm and its outside are intertwined with class, race, and gender; thus, connections of intersectionality theory and feminist Disability Studies have great potential. Intertwined with dis/ability, processes of abledment and their intersectional complexities are at the core of this conceptual paper. This paper gives a comprehensive overview of ableism as activist-theoretical concept and, based on conclusions made from the existing scholarship – often entangled with activism – to propose a feminist intersectional approach to storying ableism further.

11-05-2023

09:45 - 11:05 - **Policy and theoretical perspectives II - Identity 1**
Grand Hotel - Gullteigur A /

AGAINST ALL ODDS How can disability become a resource? A single-case study of the experiences of a young disabled man

Tone Dahl-Michelsen¹, Svein Erik Bertil Sandlien,²

¹ *Oslo Metropolitan university, Oslo, Norway*

² *Aurskog Physiotherapy Clinic, Aurskog, Norway*

Purpose: The purpose of this study is to examine how disability – against all odds - became a resource for a young disabled man and to discuss what health care professionals can learn from his story.

Design, material and method: This study is as single-case study. The book “Against Normal” written by Bjørn Hatterud (BH) makes up the empirical material. The book was

described as "a story about not fitting in, about growing up in Brumunddal and being deviant and queer in every way. This is a story of adversity and suffering, but it is not a sad story."

The analysis is thematic. Theoretically, the analysis is framed by the affirmative understanding of disability.

Findings: The findings show how difference is associated to painful experiences with the physical body. At the same time, the same physical body has produced the intellect as a resource and a positive understanding of being a disabled youth. In various ways, the relationship with his mother and grandfather has been important in relation to recognizing the disability.

Against this background, reference is made to how health care professionals can contribute to patients who do not have the same relational support as BH, and who in principle do not see disability as a resource.

Conclusion: As a young disabled person, relationships that build a positive understanding of difference have been crucial to experience life as good. There is an opportunity for health care professionals in the affirmative understanding of disability. Future studies should look at how disabled persons can understand themselves in new and appreciative ways through meeting health care professionals in the health services provided in rehabilitation services.

"I want to pretend that I'm a normal person": Disbelievability and the experiences of invisible impairments in the UK

Nick Watson¹, Shona Horton², Siannan Kerrigan³, Tom Shakespeare⁴, Heidi Smith²

¹ *University of Glasgow, Glasgow, United Kingdom*

² , ,

³ *Office for National Statistics , London ,*

⁴ *London School of Hygiene and Tropical Medicine, London, United Kingdom*

Much of the research on disability and access has focussed primarily on the experiences of those with a visible disability, one that is apparent and obvious. However, most impairments are invisible, only becoming apparent to others when people choose to reveal them or when they are exposed by barriers. Unless or until that happens, or even when that happens, people with invisible impairments can pass as nondisabled and disclosure or nondisclosure of impairment status can become an important mechanism for identity management. Unlike people with a visible impairment, who are always already discredited, they are what Goffman terms discreditable.

In this paper we draw on data from interviews with 43 people with an invisible impairment to explore and unpack their experiences as they negotiate access to activities, goods and services provided by the private sector, the barriers they face, and how these impact on their identity and sense of self. We examine how they manage these interactions, how having an invisible impairment affects their access and the stigma and discrimination they face as their impairment status is revealed. We show how disclosing disability status can bring mixed reactions ranging from pity to revulsion and ridicule making people reluctant to reveal their impairment. We also discuss how when people with an invisible impairment expose their impairment status they are often disbelieved and must prove their status to justify their entitlement to support and the impact this has on their sense of self.

In our analysis we draw on theories around stigma and discrimination and argue that while the law around reasonable adjustment and rights to access may have changed, cultural values and attitudes to disability have not. When trying to access goods and services people with an invisible are still often seen as undeserving and problematic.

From category to individual - identity support for children and youth with severe and profound intellectual disabilities

Pernille Follestad Naerø², Roald Undlien¹

¹ *Inland Norway University of Applied Sciences, Lillehammer, Norway*

² *Inland Norway University of Applied Sciences, 2624, Norway*

This study is about staff's understanding and practice of identity support in their work with children and young people with profound and severe developmental disabilities, who live in children's and respite care homes, and the significance the relationship between environmental staff and the children/young people has for this practice. Identity support means supporting the individual as a unique individual, which helps to give loved ones an understanding of who the individual is. This is particularly important for people with a profound and severe degree of developmental disability, as they need support in all areas of life - including talking about themselves. Identity support therefore becomes an important practice, if you know who the individual is, it is easier to meet the individual as themselves, and not as a representative of the category "intellectually disabled".

Following research question was formed:

How do environmental staff in children's homes understand and practice "identity-supportive interaction" with children and young people with severe and profound degrees of developmental disability?

This is a qualitative study, where seven qualitative interviews was conducted with staff who works with the target group in children's and relief homes. The findings show that although the environmental staff were not aware of identity and identity support in daily practice, their stories showed interaction with the children which could be understood as identity supporting. Continuation of the children's existing stories that had been passed down from their parents, facilitating choices and interests and developing new stories about them through face-to-face relationships were highlighted as identity-supportive practices. In order to be able to practice identity support, the relationship between the environmental staff and the children was a decisive factor, and identity support was seen as a personal responsibility.

Moral fumbling - On promoting sense of belonging to society among young adults with psychosocial disabilities

Randi Semb,

University of South-Eastern Norway, Kongsberg, Norway

Aim: The overarching aim of the thesis has been to develop knowledge that can help young adults with psychosocial disabilities to find it easier to develop a sense of belonging to society.

Method: Qualitative interviews with young adults with psychosocial disabilities and professionals in municipal health and social services.

Results: The interviews with the young adults describe dilemmas the young adults are faced with in their efforts to improve their social position: They must invalidate their previous understandings and experiences of themselves and society. Among the young adults, there are different opinions about whether this is right and reasonable to demand. The professionals assume that the young adults must increase their skills and set themselves realistic goals for the future. At the same time, professionals find it problematic that they cannot take young adults' goals and wishes as a starting point and are unable to offer them the same future prospects as their peers.

Discussion: All the interviews point in the direction that the young adults' understanding of reality and expectations can be an obstacle to achieving sense of belonging to society. The results indicate that a central theme in negotiations between young adults with psychosocial disabilities and professionals about how society belonging should be promoted will depend on the extent to which the individual young adult's understanding of reality is to be recognized "as it is". It seems necessary to develop a society and services that accommodate young adults in different and better ways than what seems to be the case today. I also argue that some "standards" should be developed for when it is legitimate to young adults with psychosocial disabilities to demand changes in society.

11-05-2023

09:45 - 11:05 - **Culture and history I - Disability in historical context**
ÖBÍ 2 - Sigtún 42 /

A historical investigation on the Special Care System in Denmark in the time from 1933 to 1980.

Klaus Petersen², Annemarie Borregaard¹, Mette Seidelin¹, Sarah Smed³, Poul Duedahl⁴

¹ *Danish National Archives , Copenhagen, Denmark*

² *University of Southern Denmark, Odense, Denmark*

³ *The Danish Welfare Museum, Svendborg, Denmark*

⁴ *University of Aalborg, Aalborg, Denmark*

In 1933, the Special Care System ("Særforsorgen") was established as care provider and care administrator for six groups of people with the following disabilities: blindness, deafness, epilepsy, speech impediments, intellectual and/or physical disabilities. The state driven system closed in 1980.

In March 2022, a historical investigation on the Special Care System, ordered by the Danish government, was published. After two years of research, the conclusion was clear: the research group documents a large number of examples of abuse and neglect. Eg. Violence, sexual assault, unnecessary use of force such as fixation and confinement. This was especially the case for people with intellectual disabilities.

The research shows that despite the fact that the state took over the responsibility of the Special Care System, no systematic control was carried out by the state. Testimonies given

in interviews state, that the placement has had negative consequences for the lives of the persons who had been institutionalised both during and after the placement.

The conclusion is based on a big amount of historical documents in the Danish National Archive and interviews with a large number of persons with disabilities, relatives and staff members from institutions.

The purpose of my presentation is to present the historical inquiry, the conclusions and some qualified explanations for the findings. I will also present the ethical dilemmas discussed in the research group.

Changing conceptualizing of care policies for persons with disability in Norway-1920-2020

Marte Feiring,

Oslo metropolitan University/ Diakonhjemmet Hospital, Oslo, Norway

This paper explores how the terms 'ability/disability' and 'care' were used in Norwegian policy documents for persons with a disability. Following Bourdieu (1977)^[1], we see 'disability care' as a 'field' and a 'social space' for struggles over forms of 'capital' or knowledge, for example, a care regime is seen as a product of struggles between the traditional knowledge practices (*orthodoxy*) and the new knowledge practices (*heterodoxy*).

Four documents are analysed by applying historical text analysis. The disability care in Norway (1922-24), The Disability Care Committee reports (1953/56); Disabled persons in Society, White Paper (1977/78); and the Report "From user to citizen" (2001/2002).^[2] The analysis of the texts is organised around the changing *discourses* of the terms ability/disability and care policies. The papers include how Norwegian policies are informed by other countries are addressed.

The preliminary findings are that before the 1940s, the policies in this prevailing care regime were influenced by social hygienic discourse. The main policies in the 1950s were written in a socio-medical framework, while the main discourse of the late 1970s was social integration in the community. Finally, the document published around the year 2000 applied the rhetoric of 'users', and 'citizens', and highlighted the distinction between impairment and disability.

^[1] Bourdieu, P. (1977). *Outline of a Theory of Practice*. Cambridge: Cambridge University Press

^[2] Vanføreforsorgen i Norge, 1922-24, Vanføreomsorgen i Norge, 1953-56, Funksjonshemmede i samfunnet, 1977-78, Fra bruker til borger, 2001

Intersecting minority positions: The case of disability and Finland-Swedishness in the mid-20th century

Hanna Lindberg,

Tampere University, Tampere, Finland

In this paper I study the intersections between different minority positions in mid-20th century Finland, by focusing on people with disabilities belonging to the Finland-Swedish minority. Finland was (and still is) a bilingual country with both Finnish and Swedish recognized in the

constitution as national languages. During the 20th century, the number Finland-Swedes, however, continually decreased, constituting only 6 % of the population by the end of the century. Before the war, Swedish-speakers had belonged to the most vocal proponents of race biology and eugenics, working for the racial cohesion of the Finland-Swedish minority in Finland and against physical and mental impairments. Furthermore, Finland-Swedish doctors and scientists were actively involved in the preparation of the Finnish Sterilization Act of 1935. The end of the second world war, however, saw the expansion of disability rights, and the improvement of care for people with both physical and intellectual disabilities. These rights were to be realized for both Finnish- and Swedish-speakers, and would lead to a reconceptualization of the position of people with disabilities within the Finland-Swedish minority.

In the paper I explore the changes that occurred during the decades after the second world war, which can be seen as a transitional period both in relation to the treatment of people with disabilities and language relations in Finland. I focus on the ways in which eugenic discourse was slowly replaced by notions of care within the Finland-Swedish minority, and how people with disabilities started to assert their rights by claiming the position of a minority within a minority.

Few Steps Closer to Inclusive Society: Design for Social innovation. Case Study

Ieva Rosne,

Art Academy of Latvia, Riga, Latvia

Few Steps Closer to Inclusive Society: Design for Social innovation. Case Study

Thirty years after the restoration of independence Latvian society is still influenced by the consequences of the Soviet legacy when isolating people with intellectual disabilities was part of The Soviet ideology (Peters & Hagenburg, 2014). Data shows that stigma, social isolation and discrimination are still reality for many people with mental disabilities and their families in Latvia.

This paper discusses/presents/analyses social innovative solutions for people with mental disabilities and their families in Latvia, created and put in practice using design methods and approaches. Author carried out a project with purpose to create research based practical solutions for improving quality of life of people with mental disabilities in Latvia.

Triangulation of the methods helped to look at the research topic from different points of view and to create a diverse set of data. Ethnographic research was conducted to find out the needs, skills, strengths and weaknesses of the users. Keeping in mind that one of the ways to contribute to the development of an inclusive society is to design innovative social solutions (Manzini, 2014) author applied design methods taking into account the specifics and lifestyle of people with mental disabilities as the target audience. In order to promote the effectiveness of the solution, which is aimed at directing a targeted activity, fostering its development and competitiveness on the market, as well as for the solution to be useful, desirable and effective, service design methods were used. During the development of the project, creative workshops were organized using social design methods and creative thinking methods for target audience research. The developed solution was an innovative employment model. Prototyping and testing of the model in focus groups as well as implementing various inclusive public activities was carried out for the model to be realized in practice.

Although the results for this solution will only be perceivable on the long run, it is clear that we are taking steps closer inclusive society.

Thus realizing the idea of acceptance in a different way and realizing the value of each person as an individual, the author focuses on creating a socially inclusive environment (Siebers, 2008) taking into account the basic principles of universal design.

11-05-2023

09:45 - 11:05 - **Work and employment I - Quality of Employment of People with Disabilities** Hilton Nordica meeting room I /

- Moderator: Sophie Teborg, Federal Institute for Occupational Safety and Health
- Moderator: Lena Hünefeld,

The Implications of Classroom Type and Education Level on the Intention to Work among Young Adults with Physical Disability

Limor Gadot¹, Yifat Faran², Orly Sarid³

¹ *Sapir Academic College, Gevim, Israel*

² *Ashkelon Academic College, Ashkelon, Israel*

³ *Ben-Gurion University of the Negev, Be'er Sheva, Israel*

Background: The participation rate in the Israeli labor market of people with (53%) and without disabilities (80%) is disproportionate. Integrating young people with disability in the labor market is accompanied by social barriers such as type of classroom in childhood as well as high education which can be related to the intention to participate in the labor market.

Objective: 1. To examine the relations between onset of disability, education level, type of classroom (inclusive/integrated class in mainstream education, class in special education system) and the intention to work. 2. To test a mediation model between onset disability, type of classroom, level of education and intention to work.

Participants: 250 young Israeli adults with a physical disability, 182 with congenital and 68 with late-onset disabilities. Ages 18-32, ($M = 24.8$, $SD = 3.16$), recognized by the National Insurance Institute who have not yet integrated in the labor market.

Procedure: The participants completed a questionnaire reporting the onset of disability, type of class they attended and their education level, as well as their intention to work.

Findings: Structural equation modelling was used to examine both direct and indirect effects of onset disability, type of classroom and education on intention to work. Participants with congenital disability exhibited weaker intent to join the labor market than did those with late-onset disability. This relationship was mediated by type of classroom and education level. Participants with congenital disability who had studied in special education settings during their school years had less high education and weaker intent to work in the labor market.

Discussion: The findings shed light on the long-term implications of social construction conceptualization indicating that once students are tracked into special education setting

their adult academic education and intention to work are affected. Implication for policy will be discussed.

Increasing the Transition Rate of People with Disabilities into the General Labour Market - Three Innovation Approaches

Bastian Pelka, Lisa Preissner, Ann Christin Schulz

TU Dortmund University, Dortmund, Germany

For people with disabilities it is more difficult to access the general labour market. However, different target groups are affected to different degrees by this exclusion. While people who acquire a disability in working life often remain part of the labour market, labour market access is much less successful when people acquire a disability before they first enter the labour market.

In Germany, there is an established system of workshops for people with disabilities that simultaneously offer training and help with the transition to the labour market. In the wake of the UNCRPD, expectations are rising to shift from a work related separating function to an empowering function. However, workshops rarely succeed in creating transitions to the general labour market.

This is where the project "Working the way I want to" comes in: The aim is to empower people who work in a workshop for people with disabilities to independently identify and follow a path to their own desired occupational career.

The project uses three instruments for this purpose:

In real labs, experts from design science and rehabilitation science work with people with disabilities on labour market related questions. The aim is to empower people to learn about their own wishes and rights.

An AI-supported app will present already available support options, aids and support programmes as well as the rights and entitlements of the target group in such a way that people with disabilities can use the app to plan their career goals.

A sociological study of workshops and companies in the general labour market, as well as of actors from politics and civil society, will identify obstacles on the way to employment for people with disabilities and test countermeasures.

The presentation will introduce and discuss the project as well as its methodology and first results.

International Research on the Work Situation of People with Disabilities – A Scoping Review

Sophie Teborg, Lena Hünefeld

Federal Institute for Occupational Safety and Health, Dortmund, Germany

Well-designed working conditions are an important factor for the quality of work and of great importance for the well-being of employees. While numerous studies are available for people without disabilities in this context, the state of research for employees with disabilities hardly

allows detailed statements about their work situation. To shed light on disabled people's quality of work, this scoping review aims to bundle internationally existing findings with respect to different (1) study designs, (2) types of disabilities, (3) work contexts and (4) working conditions. A scoping review applying Arksey and O'Malley's (2005) framework was conducted. The databases PsycArticles, PsycInfo, PSYINDEX, PubMed and Embase were searched to identify relevant studies published in English and German between the years 2017–2022. To be included, a study had to examine at least one working condition of people with some kind of disability in a competitive employment setting. Studies focusing on transitional processes (i.e. hiring, return-to-work) were excluded. Most of the studies were cross-sectional, primary research. Samples often solely focused on people with disabilities while comparisons between workers with and without disabilities were rather rare. Thereby, studies covered a wide variety of work situations and workplace challenges for people with different disabilities. Psychological and physical disabilities were examined more frequently than intellectual or sensory ones. Regarding working conditions, the social environment was the most prominent topic while aspects like work tasks or technical equipment were less represented. The great emphasis of the social environment in the studies indicates that this topic is especially important for the work situation of people with disabilities. Future research should note this, but not neglect other important working conditions like flexibility or chances for personal development. Overall, studies should sharpen their approaches and focus on producing more in-depth findings to understand issues rather than just uncovering them.

Factors Influencing the Inclusion of People with Disabilities in Companies – An Empirical Analysis Based on the 2018 BIBB/BAuA Employment Survey

Christiane Flüter-Hoffmann, Andrea Hammermann, Roschan Monsef

German Economic Institute, Cologne, Germany

The Coronavirus pandemic has shone a spotlight on the extreme importance of social cohesion and professional interaction in the workplace for employees' well-being and job satisfaction. Occupational participation is a mainstay of social inclusion, and this is especially true for people with disabilities. Furlough schemes, being forced to work from home, social distancing and the consequent isolation pose a particular challenge for those with impairments, since in many cases they thus forfeit a sense of community and opportunities to bond with a team. Based on the 2018 BIBB/BAuA Employment Survey, this study examines the significance of a supportive and inclusive working atmosphere for employee job satisfaction and the importance of various influencing factors, particularly for people with disabilities. The results show that staff members who regularly perceive their superiors as supportive and frequently experience a sense of community are significantly more satisfied with the opportunities offered by their work to make use of their skills. This applies to a greater extent to employees with disabilities than to those without. Personnel measures such as the offer of workplace health promotion also increase the likelihood that employees will be generally satisfied with their work situation – again, this is significantly more often the case for staff with disabilities than for those with none.

Chances and Challenges for the Inclusion of Employees with Chronic Conditions from an HR Managers' and Line Managers' Perspective

Henrike Schmitz, Mathilde Niehaus

University of Cologne, Cologne, Germany

Background

Chronic conditions are widespread. About one-third of the European working population is affected by them (Eurostat, 2019). Research on the perspective of employees with chronic conditions shows the necessity for improvement regarding the quality of work and equal inclusion of employees with chronic conditions (e.g., Dettmann & Hasselhorn, 2020).

HR- and line managers are gatekeepers for the employability and inclusion of employees with chronic conditions. However, their perspective has been insufficiently studied so far. Therefore, this research aimed to investigate the chances and challenges at the company level regarding the inclusion of employees with chronic conditions.

Methods

From November 2021 until March 2022 semi-structured interviews with line managers and HR managers ($N=16$) from medium-sized companies were conducted. The interviews were analyzed using the qualitative content analysis by Kuckartz (2018) in an inductive-deductive procedure.

Results

Demand-oriented job design is a key element for the quality of employment of workers with chronic conditions from a managerial perspective. Within the job design, HR- and line managers have several opportunities for reasonable adjustments - such as the flexibilization of working conditions - to support employees with chronic conditions. Yet, e.g. specific work activities, occupational sectors or the lack of experience are challenging factors for designing a better workplace.

Furthermore, an open communication culture about health-related topics and raising awareness for chronic conditions among HR- and line managers were identified as inclusion-critical factors.

Discussion

The perspective of HR- and line managers opens a broader view on the inclusion of employees with chronic conditions and the quality of employment. This perspective should be further examined in future research and should also be considered in recommendations for action. Knowledge and awareness regarding chronic conditions at the workplace must be fostered along HR- and line managers to promote the quality of work for employees with chronic conditions.

11-05-2023

**09:45 - 11:05 - Deafness I with International Sign Language -
Deafness as an experience, epistemic practice and as creative
force. Eastern European micro-stories** Grand Hotel - Háteigur /

- Moderator: Natalia Pamula, U of Warsaw

Polish Independent Deaf Filmmaking

Magdalena Zdrodowska,

Jagiellonian University, Krakow, Poland

The interrelations between cinema and deafness are mutual and complex, and usually remain outside the main interest of both film and deaf studies. If film and deafness intersect film studies tend to consider deaf people and deaf communities mainly as audiences that require assistive technologies to enjoy film, while deaf studies concentrate on the representations of deafness and deaf characters in film. In both cases, deaf people tend to be considered rather consumers of cinematic culture than its creative force. Yet, deaf people were and still are active filmmakers.

In my presentation, I will discuss the independent deaf film movement that flourished in Poland under the communist regime, in the transformation era, and is present today. I will relate to the amateur filmmaking movement in the United States since the beginning of the twentieth century. In both cases, the deaf communities were organized nationwide, hence centralized associations (American National Association of the Deaf and Polish Association of the Deaf) influenced the film making practices of its members.

Independent deaf filmmaking will be investigated in relation to the specific political, cultural, and organizational environment in which deaf films were produced, distributed, and viewed. I will also consider the very concept of independent deaf films, especially how 'independence' can be understood in relation to films produced within the centralized, state-controlled association.

In the presentation I will use articles from the Polish deaf press, ethnographic interviews I have conducted with filmmakers, and present film excerpts for micro-analyses.

Deaf in Postwar Romania: Between socialist utopia and marginality (1948-1989)

Radu Dinu,

Jönköping University, Jönköping, Sweden

As compared to deaf history in the western world, the experiences of the Deaf community in Romania have scarcely been explored by historians. Certainly, new research on disability in Eastern Europe has enriched our understanding and contributed to de-center Western narratives during the last years. However, the history of the Deaf in Central and Southeastern Europe still needs to be written. In my presentation, I will explore the ways in which the Deaf community in Romania accommodated itself to state socialism (1947-1989). Drawing on the deaf association's own periodicals, the "Deaf-Mutes' Newsletter" (*Gazeta Surdo-Muților*), "Our Life" (*Viața Noastră*), and unpublished archival documents from the Romanian National Archives, this paper traces the ways in which the Deaf responded to political expectations from above and inscribed themselves into the socialist value system. Against this backdrop, two aspects will be particularly highlighted: Firstly, I will discuss how an emerging Deaf identity and culture was articulated and how it interacted with socialist visions of equality, morality and justice. Secondly, I will investigate how sign language and oralist teaching methods, the latter of which dominated much of deaf education during that period, were discussed and negotiated by the Deaf community.

The right to work: deafness, disability, and the contingencies of neoliberal inclusion in contemporary Poland

Natalia Pamula,

University of Warsaw, Warsaw, Poland

My presentation focuses on recent Polish discourses concerning disability, deafness, and the right to work. I will analyze a 2019 campaign organized by the Polish Deaf Society that promoted employment of deaf individuals and 2022 articles of a mother, Agnieszka Szpila, of two disabled daughters who in order to provide care to her children was forced to give up work. Both the campaign and Szpila's articles emphasize the importance and value of work to disabled and deaf communities and the caregivers of disabled subjects. The campaign and the articles highlight not only the right to work, but also a desire to participate in society via work.

I center the self-fashioning as efficient and productive employers by deaf individuals and the parents of disabled children and unpack the meanings attached to work which are present in these cultural texts. My presentation thinks of disability as a relational experience and asks: how do disabled and deaf subjects insert themselves—discursively—into the world of labor in contemporary Poland? How does work operate in these two examples and why is it seen as the most desired route into society? What is the cost of the neoliberal inclusion hinging on work? What differs my analysis of work and disability from those produced in Western locations is a post-socialist context and the question of care. I am interested in thinking about what it means to be forced *not* to work as a caregiver of disabled subjects or not given a chance to work as a deaf person in a society in which, historically, there was a right to work but no corresponding right *not* to work. I am also thinking about the intricacies of care and its relationship with work.

Deafness, public health, and technologies of science communication in Poland, 1950s-2020s

Sławomir Łotysz,

Polish Academy of Sciences, Warsaw, Poland

Limited access to audible information makes deaf people particularly vulnerable to health risks. Throughout most of the 20th century, a communication barrier between them and health workers, as well as limited access to official media channels such as radio and television, has been affecting both their ability to take prophylactic measures on an individual level and raising collective awareness of epidemic threats. The patterns of this communicative exclusion, as well as means of overcoming it, have changed over time. Recently, such modern digital technologies as mobile phones, social media, and video chat platforms have significantly augmented visual communication preferred by the deaf. Nevertheless, they still experience the significant barriers in access to information, especially official medical knowledge, and state policies regarding it. Additionally, during COVID-19 pandemic, when the deaf could not supplement their communication practices by means of lip-reading in interpersonal communication with the hearing due to obligatory face mask policy, even their access to informal circulation of information got worsened.

Understanding how the communicative exclusion of the deaf from medical knowledge has been dealt with by the state and the deaf themselves in Poland is one of the objectives of a research project "Media and epidemics: Technologies of science communication and public health in the 20th and 21st centuries" conducted within the CHANSE network.

In this paper I will seek to place the project's preliminary findings within a broader international context and propose a theoretical frame on the intersections of disability studies, science communication and health diplomacy. I will argue that consent to the continued existence of barriers to the deaf's access to medical knowledge poses a threat not only to their health safety, but to society as a whole.

11-05-2023

09:45 - 11:05 - **Policy and theoretical perspectives I - Data and policy** Hilton Nordica meeting room F /

Measuring Home & Community Based Outcomes for People with IDD and Other Disabilities

Renata Ticha, Brian Aberly,

University of Minnesota, Minneapolis, United States

The services received by people with intellectual and developmental disabilities (IDD) varies significantly across states and counties. The University of Minnesota's Research and Training Home and Community-Based Services (HCBS) Outcome Measurement (RTC/OM) has developed and engaged in a rigorous testing process of 13 person-centered outcome measures for people with disabilities, including individuals with IDD, physical disabilities, traumatic brain injury, mental health needs and aging needs. The purpose of this presentation is to share the results of a pilot and a national field study on the characteristics and psychometric properties of these measures designed to assess outcomes associated with the National Quality Forum (NQF) framework, including employment, meaningful community activity, social connectedness, and transportation. The NQF focused HCBS outcome measures developed by RTC/OM staff are person-centered, modular (i.e., intended to be used either individually or together, and consist of two tiers. Measures cover the following domains of the revised framework (RTC/OM, 2019):

*EmploymentCommunity Inclusion:TransportationHuman and Legal RightsChoice and ControlConsumer Leadership in System DevelopmentPerson-Centered Planning & Coordination*Each measure then underwent review by several technical expert panels followed by cognitive testing. During this process, each measure was assessed for comprehension, retrieval, and the adequacy of response options with subsequent revisions as necessary. The revised measures were piloted in two states with 102 participants with IDD and four other types of disabilities to test their psychometric properties. The final stage of evaluating the psychometric properties of the measures is a national field study that is currently concluding in 10 US states with a goal to reach 800 participants. The final analysis will include testing for reliability, validity, and sensitivity to change. Data indicated excellent feasibility and usability. Measures demonstrated strong inter-rater reliability, test-retest reliability, and internal consistency across participants with different types of disabilities.

Disability Data Initiative:

Minerva Rivas Velarde,

University of Geneva, Geneva, Switzerland

This presentation shall focus on presenting reports of the Disability Data Initiative.

DDI was established in June 2021 as an observatory of global disability rights. Achieving rights for persons with disabilities as stipulated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and in the Sustainable Development Goals (SDGs) requires quality, policy-relevant disability data that is 1) collected and presented by disability status, 2) based on concepts that are in line with a human rights approach to disability, and 3) reflects the diversity of people with disabilities and various aspects of their lives. There is currently no international organization or institution that produces global statistics on adults with disabilities on a consistent and systematic basis, and national statistics offices rarely disaggregate statistics by disability status.

DDI's goal is to close this disability data gap by making internationally comparable data on disability publicly available and accessible, and with this data to inform debates and facilitate policy studies. Every year, the initiative 1) collects and analyzes the disability questions in publicly available censuses and household surveys in 193 UN (United Nations) member states and 2) Produces disability rights indicators for countries with adequate comparable data disseminated on a website through data tables, maps and a report.

This presentation will focus on 2023 findings regarding human development indicators of persons with functional difficulties from Europe and Central Asia. It will also provide an overview of a number of issues regarding the risk of data bias, unethical practices and uneven data availability.

As disability disaggregated data grows, we gain insights into social equality that allows us to inform decision-making. At DDI we aim to promote good practices regarding data analysis and enhance the quality of disability data.

Social invisibility and public policies: Constructing a National Information System on Disability in Brazil

Cristina Rabelais¹, Miguel Marcelino¹, Silvia Pereira¹, Jéssica Muzy¹, Tuca Munhoz¹, José Carlos Xavier¹, Daniele Novaes¹, Sérgio Cruz², Carmem Bonifácio², Jefferson Lima², Maria Fernanda Bittencourt¹, Clara Faulhaber¹, Francine Dias¹

¹ *Fundação Oswaldo Cruz and UNIFASE, Petrópolis/RJ, Brazil*

² *Fundação Oswaldo Cruz / Plataforma de Ciência de Dados em Saúde PCDaS, Rio de Janeiro, Brazil*

In recent decades there has been an intense fight for the rights of people with disabilities, both internationally and in Brazil. Despite the achievements, this is still a segment that suffers from "social invisibility", analogous to informational invisibility, since the optimal design of public policies require the existence of reliable and periodic information, properly made available, on the characteristics, living conditions, and needs of a given population.

The objective of this work is to present methods and results of SISDEF - National Information System on Disability, a project developed to address Brazil's lack of information about people with disabilities.

During the year 2021, processes for the construction of epidemiological indicators and for the technological development of an open and universal access platform were designed and implemented, involving multi-professional, multi-institutional, and multi-sectorial teams. About 60 indicators have been built, and organized in accessible thematic panels on education, health, labor, and census data, from national data from official sources dispersed in different sectors and public agencies.

For each indicator, there is a metadata sheet that includes codifications defined on the WHO's International Classification of Functioning, Disability, and Health (ICF) bases, making it possible to identify which aspects are portrayed by the measure, that is, whether it concerns the presence of alterations in body functions and/or structures, or to the existence of barriers and facilitators in the environment, or it concerns limitations in the performance of activities or restrictions in social participation.

The project is carried out within the scope of the collaboration agreement signed between the National Secretariat for the Rights of Persons with Disabilities and the Institute of Communication and Scientific and Technological Information in Health (ICICT/Fiocruz), under the general coordination of the Research Center for Information, Public Policy, and Social Inclusion, linked to Fiocruz and UNIFASE in Petrópolis/RJ (NIPPIS/Fiocruz&UNIFASE).

Cohort Profile: The Halmstad University Register on Pupils with Intellectual Disability (HURPID)

Eva Jönsson¹, Carin Staland Nyman¹, Paul Lichtenstein², Magnus Tideman¹

¹ *Halmstad University, Halmstad, Sweden*

² *Karolinska Institutet, Stockholm, Sweden*

Knowledge about the living conditions for people with intellectual disability (ID) is limited, not least since they constitute such a small group, which puts them at risk of being invisible in the general statistics. Thus, there is a great need of a complete register of individuals in this group.

The Swedish Halmstad University Register on Pupils with Intellectual Disability (HURPID) is the first population-based, nationwide, sample of former pupils in upper secondary school for individuals with intellectual disability ($n = 26\,906$). The aim of this presentation is to provide a description of that register.

HURPID consists of pupils who were assessed as not having the ability to reach the knowledge requirements of upper secondary school, due to ID, during the academic years of 2000/2001 – 2019/2020. The cohort was established to study the transition from school to working age and to follow the development regarding living conditions, occupational patterns, and health over time.

School leaving certificates and corresponding documents of former pupils who attended the school form in question during the academic years of 2000/2001 - 2010/2011 were collected in 2011-2012. Information on national identification number, sex, program, municipality,

graduation year and complete/incomplete degree were registered. In 2020-2022, a similar data collection was carried out and corresponding information for the academic years of 2011/2012 - 2019/2020 was added (total $n = 11\,077$ women and $15\,829$ men).

So far, HURPID has been used to study occupational patterns in general (also including exploration of those not involved in employment, education, or daily activity), comorbidity, mortality, heritability, substance abuse, crime, and victimization. Future studies may, for example, examine occupational patterns over time, changes after reforms, need of support, financial situation, access to health care, comparisons with individuals with low intellectual ability (without ID), risk factors for ID and penal sanctions.

Measuring the immeasurable? Health consequences of microaggressions

Gunhild Frisell¹, Terje Olsen¹, Benedicte Kirkøen²

¹ *Fafo Institute for Labour and Social Research, Oslo, Norway*

² *Norwegian Institute of Public Health, Oslo, Norway*

In this paper, we discuss the pros and cons in a methodological design for studying health consequences of so-called microaggressions against persons with disabilities.

Microaggression refers to daily, verbal behavioral or structural slights that communicate negative, hostile, or derogatory attitudes toward stigmatized or marginalized persons or groups (Sue, 2010). Whether intentional or not, the sum of daily insults may be a repeated reminder that the person is not fitting in, and have health consequences for individuals.

Previous studies have shown that microaggressions because of the persons skin-color or gender are correlated with mental health (Nadal et al. 2014). The aim in our study is to test a method for measuring health consequences in disabled people being exposed to microaggressions.

A national survey will be distributed in emails to members of disabled peoples interest organisations in Norway during spring 2023. The survey will consist of a combination of four questionnaires, translated to Norwegian. We will test a combination of the Ableist Microaggressions Scale (AMS) (Kattari, 2020), combined with GAD-7 (measuring anxiety disorders), PHQ-9 (measuring depressions) and Mini-IPIP (measuring neuroticism).

Our methodological questions in this paper are:

- What are we possibly able to measure of consequences of microaggression?
- How can we best control for possible sources of errors?
- Are we measuring real experiences – or just general “uneasiness”?

We aim to examine the relationship between how people experience microaggressions and relate this to their self-reported mental health condition. The survey is part of a mixed-method study consisting of an online mailbox for disabled youth to report incidents of microaggressions, as well as semi-structured interviews with young people on their experiences with the same phenomenon.

11-05-2023

09:45 - 11:05 - **Childhood disability I - Caring for a disabled child** Hilton Nordica meeting room D /

- Moderator: Janikke Solstad Vedeler, Norwegian Social Research, OsloMet

The link between childhood disability and child poverty: a European comparative perspective

Julie Vinck¹, Wim Van Lancker²

¹ *KU Leuven – Centre for Sociological Research, Leuven, Belgium*

² *, Leuven, Belgium*

By ratifying the CRPD, states committed themselves to ensure an adequate standard of living and social protection to all persons with a disability, including children. Yet, prior studies showed that disabled children are more likely to grow up poor (UNICEF, 2021). This is related to the fact that these families (1) face extra out-of-pocket costs, (2) need to provide more care which impedes parental employment, and (3) often have a disadvantaged social background. Existing research has mainly focused on single-country case studies (e.g. Emerson, 2012; Houtrow et al., 2014) or comparative analyses for low- and middle-income countries (e.g. Banks et al., 2017). Due to the lack of good quality comparative data, comparative studies on poverty outcomes, its determinants and poverty reducing role of welfare state redistributive policies among disabled children in high-income countries are largely missing. These gaps are addressed in this paper. To do so, the 2017 European Union Statistics on Income and Living Conditions (EU-SILC) cross-sectional survey is used. EU-SILC is the primary reference for monitoring poverty and social exclusion in Europe and the 2017 wave includes an ad-hoc module on children's health and activity limitations due to health problems. The results show that, on average, disabled children run only a slightly higher, though non-significant, income poverty risk compared to non-disabled children in Europe. In fact, in 10 out of 31 countries the income poverty risk of disabled children is smaller than the income poverty risk of non-disabled children. These are mainly but not exclusively Eastern European countries. In all European countries, welfare state's redistributive policies play a major role in child poverty reduction for both disabled and non-disabled children. On average, the poverty reducing impact of social transfers is greater for disabled children in Europe, although this is not true in a handful of countries under study.

Contextualising income-based poverty measurement: Needs-based cost of childhood disability in Belgium

Eef Gijbels¹, Julie Vinck¹, Wim Van Lancker²

¹ *KU Leuven – Centre for Sociological Research, Leuven, Belgium*

² *, Leuven, Belgium*

Prior studies showed that disabled children are more likely to grow up poor. Yet, income-based poverty indicators, such as the often-used European at-risk-of-poverty indicator, are not necessarily a good representation of their standard of living. They are calculated on the basis of equivalised disposable household income but fail to take account of the additional

out-of-pocket costs incurred by the child's care needs. To properly understand the standard of living among families with disabled children, we develop reference budgets for adequate social participation for four hypothetical families with disabled children in Belgium. We build on existing reference budgets for hypothetical families with non-disabled children to which the additional needs and costs of childhood disability are added. To determine these additional needs and costs, we draw on guidelines, recommendations and existing scientific knowledge related to disabled children, interviews with disability experts, and focus group discussions with parents of disabled children. These reference budgets allow to estimate the cost of childhood disability from a needs-based approach and to establish a threshold that represents a minimum standard of living for these families. By comparing this threshold to the European income-based at-risk-of-poverty threshold, we are able to illustrate to what extent the latter underestimates the actual standard of living for families with disabled children. Moreover, the reference budgets allow to examine to what extent the welfare state cash support targeted at them compensates for the additional costs they face. The preliminary results show that the additional needs and costs of the families are not limited to one area (e.g., health care), but that they are situated in very diverse life domains. The hypothetical children and their families most importantly need additional support so that they are able to fully participate in society, supplemented with a number of concrete goods related to the children's specific needs.

Everyday additional costs in households caring for a child with ADHD

Marthe H. Austgulen¹, Gun Roos², Andreea Alecu³

¹ *Consumption Research Norway, Oslo Metropolitan University, Norway, Oslo, Norway*

² , ,

³ *Consumption Research Norway, Oslo Metropolitan University, Norway, Oslo, Norway*

It is well-known that living with a disability can be costly in the form of health and treatment costs, difficulties finding and keeping employment and time and energy spent on increased care needs. However, few studies have focused on the everyday household costs associated with disability. We seek to fill this gap by investigating everyday additional costs associated with caring for a child with a disability based on the budget standard approach and the theoretical frameworks of human need and capability. In this paper, we identify and explore mechanisms that lead to additional everyday household costs in households caring for a child with ADHD. The analysis is based on in-depth digital interviews with 15 caregivers raising children with ADHD aged between 9 and 16 years. The informants were recruited through social media and the voluntary organization ADHD Norway. Each informant was interviewed twice and between the interviews, the participants were asked to review a booklet presenting detailed information about goods and services associated with a decent standard of living as operationalised in the Norwegian Reference Budget. The preliminary findings demonstrate that while many caregivers initially said that they do not have major additional costs as a result of the child's diagnosis, a range of additional needs and costs became evident throughout the interviews. Three main types of additional costs were identified: Immaterial, material, and indirect costs. Additional immaterial costs include increased time use and stress, and reduced quality of life. Additional material costs followed from the increased need to replace things, fix, and protect equipment, test and try out food, equipment, and leisure activities and from using more of certain goods and services such as toiletries and electricity. Some reported significantly increased housing costs. Additional indirect costs include a reduced work schedule and reduced career ambitions.

Estimating direct and out-of-pocket costs of living with a disability: A scoping review of the literature

Andreea Alecu, Marthe H. Austgulen, Gun Roos

Consumption Research Norway, Oslo Metropolitan University, Norway, Oslo, Norway

Living with a disability or caring for a person with a disability is associated with an increased risk of living in poverty, and elevated poverty rates are often attributed to lower incomes and higher out-of-pocket (OOP) expenditures for persons with disabilities. With the aim of informing and supporting the development and targeting of disability policies, the literature on the costs of disability is growing. However, previous reviews have found that the field of research is fragmented as the methods and measures used to assess additional costs vary considerably between studies. The objective of this paper is to review the part of the literature on the costs of living with a disability focusing on the costs covered by the individual or their households. We extract relevant articles from Medline, PsycINFO, Embase, Cochrane Reviews, Scopus, and Econlit databases published from January 1990 to December 2022 and conduct a scoping review following the PRISMA guidelines. We aim to 1) provide an overview of the methods that have been used to identify costs, 2) map which types of costs the studies have identified, and 3) evaluate the interaction between the methodological approach and identified costs, as well as the strengths and weaknesses associated with the identified approaches. The search revealed 100 studies that measure direct or out-pocket costs. Preliminary results indicate that few studies have an explicit definition of direct or OOP costs, and few studies compare costs between disabilities, or to a control group of non-disabled persons. Most studies have a cross-sectional design and employ quantitative methods. Overall, this review presents evidence that disabilities are indeed associated with increased out-of-pocket costs for persons living with a disability and their households. However, these costs vary considerably between methods and countries. Future research to develop comparable standards is necessary.

11-05-2023

**09:45 - 11:05 - Education I - From disability focused to justice focus
– 12 years of international collaboration** Grand Hotel - Muninn /

- Moderator: Tal Jarus, University of British Columbia

Connecting with communities to create change for success

Elizabeth McKay¹, Laura Bulk², Tal Jarus², Anita Atwal³, Vimal Sriram⁴

¹ *Edinburgh Napier University, Edinburgh, United Kingdom*

² *University of British Columbia, Vancouver, Canada*

³ *London Southbank University, London, United Kingdom*

⁴ *UHBW NHS FT, Bristol, United Kingdom*

Background/Purpose

Over the past decade the need for the recipients of health and social care to be full participants in research that meets their needs and wishes has become paramount. Research co-production is about doing research with those who use it (Graham et al 2019) and those whom the research is about (Involve 2018). Such a model of collaborative research involves the active participation and partnership of all parties, following the motto “nothing about us without us.” It gives researchers a better understanding of the issues, solutions, and contexts (Oliver et al 2019). This involves working with the community and hearing their perspectives regarding what is important to them and how they can participate fully in the whole research process, from the outset.

Methods

This session will highlight two examples of how we have connected with communities to bring about change. The first example engaged with Black Asian and Minority ethnic (BAME) Occupational therapists. This group has been identified as being subject to racism, microaggression and discrimination regularly within their workplace. Therefore, at the outset of the work it was key to engage the community to build understanding regarding the value of the research question, and its relevance, importance, and acceptability to BAME occupational Therapists. The second example we will share involved an early-career blind scholar, who engaged the blind community in determining the directions for her doctoral program of research. The resulting ‘insider’ research explored being blind and belonging in academia, and also involved blind community members in the co-creation of knowledge sharing activities.

Conclusions

For both examples, the processes of engagement, challenges, and outcomes will be presented and we will discuss the cruciality of community engagement to research moving toward Justice, Equity, Diversity, and Inclusion.

Modifying existing environment and resources to create change for success

Clodagh Nolan ¹, Michael Lee², Kieran Lewis¹

¹ *University of Dublin, Trinity College, Dublin, Ireland*

² *University of British Columbia, Vancouver, Canada*

Background/Purpose

Research has shown that disabled students in higher education can face many challenges in participating and engaging in their studies. By adapting and improving the learning environment students can be supported in their wellbeing which can enhance their ability to partake and be successful in their academic work. In this presentation, we will present two projects that have targeted the environment as a means of improving well-being for disabled students.

Methods and Results

The first project was implemented at Trinity College Dublin, the TCD Sense Project, which aims to make Trinity College more inclusive by reviewing and improving new and existing spaces, building sensory awareness, and delivering specialist supports. This project was developed following extensive research with disabled students and an audit of the university's spaces. The presentation will focus upon sharing the approach and design of the

project as well as the tools developed. In the second project, the University of British Columbia developed an initiative to identify teaching practices that support student wellbeing and foster a healthier learning environment. A large-scale mixed methods study was implemented based on an extensive literature review to identify teaching practices that support students' wellbeing. Using the findings, the research team developed tools for professors to adopt these practices in their day-to-day classes. In this short presentation, participants will learn about these tools and contextualize the practices to fit their specific context. Principles of the findings are also applicable beyond post-secondary institutions.

Conclusion

Modifying the learning environment improves students' learning experience and academic success, especially for disabled students. These studies also contribute to the understanding of the universal design of learning to benefit not only disabled students but also to address justice, equity, access and inclusion.

Working on the system level to create change for success

Michael Lee¹, Clodagh Nolan², Naomi Schreuer³, Susan Cox¹, Matthew Smithdeal¹, Kieran Lewis⁴, Declan Treanor⁴

¹ *University of British Columbia, Vancouver, Canada*

² *University of Dublin, Trinity College, Dublin, Ireland*

³ *The university of Haifa, Haifa, Israel*

⁴ *Trinity College Dublin, Dublin, Ireland*

Background/Purpose

Enabling the participation of disabled students and clinicians in health and human professions cannot be completed just by working on individual needs. Justice, equity, diversity, and inclusivity root at a system level. Hence, fostering the participation of disabled and other equity-denied people requires working from a system level. In this presentation, we will share three success stories highlighting the importance of systematic advocacy and spark further discussions on effective ways to bring system changes.

Method and Results

The research team at the University of British Columbia used research-based theatre to bring out the contentious issues of inequity among disabled students and faculties and other discriminated groups. Using theatrical performance, inequity concerns are discussed openly in a safe and supportive environment, with actions identified. Theatrical performance avoids viewers talking about their personal experiences, promotes an appreciative inquiry approach and move the discussions to explore system-level solutions. This approach is welcomed by faculty, students, and university's administrators.

By building collaborative teams at the University of Dublin (Trinity College) it has been possible to develop a university-wide system of support for disabled students and to address inequalities in the system. This presentation will show how collaboration across the university as well as a transformational approach to service delivery has resulted in better learning spaces for students.

At the University of Haifa, cleaning-service workers (mostly women from equity denied groups) were transferred from outsourcing to direct employment. This presentation will

demonstrate how students in an occupational therapy ergonomic course worked towards enhancing the awareness of decision-makers and the campus public regarding the physical and psychosocial risks cleaning workers face.

Conclusion

Bringing all stakeholders to the discussion table enables open dialogues and willingness to make changes, not only at the individual level but at the system level, resulting in more sustainable and long-term impacts.

Sharing knowledge to create change for success – use of stories, theatre and Visual Time Capsules

Tal Jarus¹, Laura Bulk¹, Laen Hershler¹, Yael Mayer², Doris Fox¹, Justin Turner¹

¹ *University of British Columbia, Vancouver, Canada*

² *The university of Haifa, Haifa, Israel*

Background/Purpose

Using innovative knowledge translation (KT) activities in ways that are accessible is integral to ethically collaborating with equity-denied communities and increasing their access to and participation in knowledge building. Two projects will demonstrate such accessible KT activities.

The first example aimed to facilitate attitudinal change and reshape policy in support of disabled students and clinicians in the health professions via a KT method that would reach both the brains and the hearts of audiences.

In the second example, after we presented the analyzed transcripts from a program aimed at decolonizing and Indigenizing health professions academic programs, our Indigenous Elders expressed the need to present results with cultural takeaways and in a way that humanizes participants' learnings and contributions.

This presentation aims to describe the identification, implementation, and evaluation of innovative KT of academic, qualitative research findings from those two projects, to wide audiences, including higher education programs, policy makers, and partnered communities.

Methods

We used Research-Based Theatre, Composite Character Stories, and a Visual Time Capsule. Each element presented a syntheses of compiled participant quotes, representing themes that we identified in previously-analyzed transcript data. The end results - a theatre play, stories of fictitious participants, and an illustrated video - were developed with input from the community, through numerous synchronous and asynchronous discussions. The impact of those KT methods was evaluated via surveys and interviews.

Results

Results indicate significant changes in attitudes and knowledge about the disseminated topics. Feedback from participating communities demonstrated those innovative methods are accessible to a wide audience.

Conclusions

These innovations contribute to our understanding of culturally-relevant and accessible methods for future KT and research dissemination projects. This can help build stronger research partnerships with equity-denied communities and improve access to health services.

11-05-2023

09:45 - 11:05 - **Disability and the lifecourse I - IMAGE Project and beyond: Supporting autistic university graduates into work** Hilton Nordica meeting room H /

- Moderator: Mitzi Waltz, Athena Institute

Impact and Lessons Learnt from the IMAGE Project: Improving Employability of Autistic Graduates in Europe

Marc Fabri¹, Mitzi Waltz², Henri Pesonen³, Bertrand Monthubert⁴, Timo Lorenz⁵

¹ *Leeds Beckett University, Leeds, United Kingdom*

² *Vrije Universiteit Amsterdam, Amsterdam, Netherlands*

³ *University of Oslo, Oslo, Norway*

⁴ *University of Toulouse, Toulouse, France*

⁵ *Medical School Berlin, Berlin, Germany*

Autistic young people are entering Higher Education at an increasing and unprecedented rate. This student group is generally motivated and academically competent, yet at the end of their studies they face a significant employment gap, or employment below the qualification they have gained. This prevents personal fulfilment, and is a loss to society and the economy.

The reasons are multi-fold: Careers advice is not tailored well to this group, academic tutors lack understanding of how best to support autistic students to develop employability skills or gain work experience; employers' recruitment procedures create barriers; and employers are unsure how to support autistic graduates in the job. Further, autistic graduates themselves may be unsure of their support needs, and how to talk about their autism.

For the Erasmus+ funded IMAGE project (www.imageautism.com), five European universities collaborated with autistic people and those involved in their support to co-create a range of hands-on resources: (1) an employability toolkit for autistic students and graduates, (2) autism training materials for careers advisors, and (3) good practice guides for academics, employers and careers advisors. These resources focus on strengths rather than deficits, on a better understanding of autism, and for the autistic graduate to develop self-advocacy and self-determination skills. We included several case studies that demonstrate what good support practice looks and feels like.

The IMAGE resources were launched in February 2022 and are available in five languages. Initial feedback indicates that they improve the understanding of autism, of reasonable adjustments, of workplace challenges, and the importance of focusing on strengths. Professionals appreciate advice on how to communicate more clearly and effectively, whilst

autistic people like the career planning tools. By the time of the conference, we will look back at one year of use and be able to report on the resources' more permanent impact.

Autistic graduates: Graduate capital and employability

Henri Pesonen¹, Tarja Tuononen², Marc Fabri³, Minja Lahdelma⁴

¹ *University of Oslo, Oslo, Norway*

² *University of Helsinki, Helsinki, Finland*

³ *Leeds Beckett University, Leeds, United Kingdom*

⁴ *Heureka - The Finnish Science Centre, Vantaa, Finland*

An unprecedented number of autistic people are completing university, and they frequently face unemployment after graduation. However, research focusing on the forms of graduate capital and their employability is scarce. The focus of existing research has been on non-autistic, or neurotypical, graduates. The human, social, cultural, identity and psychological capital might be different for autistic graduates due to the characteristics of autism.

Using a participatory approach, our aim was to examine the five areas of graduate capital in the context of autistic graduates. The study involved semi-structured interviews with 15 autistic university graduates from England, Finland, France and the Netherlands. Data were analysed using theory guided content analysis and 'data driven' approaches.

The five areas of graduate capital are of relevance to autistic graduates, who typically expose gaps in multiple capital. Although the graduates were from four European countries, they evenly endorsed each of the five capital areas investigated, and the issues related to them. Thus, there were no cross-country differences. Earlier research indicates that these five forms of capital as cumulative and recursive, giving an advantage to graduates who cover all five areas well. This puts autistic graduates at a disadvantage because it constitutes a wider issue of whether autistic graduates actually 'lack' competencies in any area of graduate capital, or whether graduate capital are a construct borne out of the expectation to meet certain societal norms – a construct that ought to be challenged.

Various important areas that need to be considered when improving inclusive services and the university curriculum to accommodate autistic individuals better. Such improvements and adjustments will clearly benefit all university students and graduates.

Roadblocks and roundabouts: Addressing the normative gatekeeping function of HR to achieve employment for autistic graduates - Mitzi

Mitzi Waltz, Elena Syurina

Vrije Universiteit Amsterdam, Amsterdam, Netherlands

For three years, the IMAGE Project team looked at steps that could be taken to support autistic graduates in their search for graduate employment. We co-created training materials for careers advisors and delivered training, we developed a well-received toolkit to help autistic students improve their employability, we liaised with employers who want to attract a neurodiverse workforce, we documented best practices, and we examined other barriers to finding graduate employment.

There was one key location that our efforts could not reach, and it emerged as a major barrier: current norms, values and practices in corporate and academic Human Resources. In discussions with autistic graduates, careers advisors and employers, this barrier was mentioned again and again. Although some companies, especially in ICT, have recognized the value of neurodiverse employees, this was found to often be in the context of “special” workplaces or alternative hiring trajectories. Mainstream HR, however, has continued to adopt practices that actively exclude neurodiverse applicants. These include use of personality tests (e.g. Myers-Briggs, Enneagram) that are inherently biased against autistic strengths; focusing on social skills, even when not relevant to the post; use of nebulous criteria such as “team fit”; and reliance on interview procedures that can be intimidating and anxiety-producing. Coupled with existing prejudice against neurodiverse applicants¹, these practices make discrimination against autistic graduates structural.

In this presentation, we will discuss the next step to ensuring employment for these highly skilled graduates: tackling the problem of disabling HR practices.

¹Institute for Leadership & Management (2020) *Workplace Neurodiversity: The Power of Difference Part 2: Perceptions About Neurodivergents*. Online: <https://www.institutelm.com/resourceLibrary/Neurodiversity2>

11-05-2023

09:45 - 11:05 - **Policy and theoretical perspectives III - Paradigms and conceptualisation 1** Grand Hotel - Gullteigur B /

Making Disability Matter

Dan Goodley, K Runswick-Cole, Rebecca Lawthorn

University of Sheffield, Sheffield, United Kingdom

This paper reflects on our aspirations to transform health research and environments through a paradigm shift; from disability as problem to disability as *the* driving subject of inquiry. Established fields such as medicine, medical humanities, health psychology, medical sociology, population and public health studies conventionally understand disability as a problem requiring a solution. Research emerging from these fields renders disability as an object of inquiry. This is true even within everyday life where disability is understood as an unfortunate happenstance requiring remedy. We propose a paradigm shift: rather than conceiving of disability as the passive object of inquiry, we understand disability as the driving active subject of inquiry. This proposal for a paradigm shift will be familiar to many scholars within critical disability studies but we suggest that our own field is in danger, at times, of objectifying disability in ways that lead to what Stiker (2019) describes as disability’s erasure. In response, we reflect on three new funded projects to contemplate what it means to make disability matter: theoretically, methodologically, pragmatically and politically.

Project 1 - Humanising the healthcare of people with learning disabilities

<https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/home>

Project 2 - Tired of Spinning Plates? A project to understand and improve the mental health experiences of carers of adults with learning disabilities.

<https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/home>

Project 3 - Disability Matters

Website to be launched at NNDR 2023

We conclude with some further considerations for key concerns in critical disability studies building on a previous paper (Goodley et al, 2021).

References

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2021). Key Concerns for Critical Disability Studies. *The International Journal of Disability and Social Justice*, 1(1), 27–49. <https://doi.org/10.13169/intljofdissojus.1.1.0027>

Stiker, H. (2019). *A History of Disability*. Ann Arbor: The University of Michigan Press.

Enabling Futures: Exploring the potential of the Sociology of the Future for Disability Studies

Hannah Morgan,

Centre for Disability Studies, University of Leeds, Leeds, United Kingdom

While the Disabled People's Movement and Disability Studies have long been concerned with articulating and realising enabling and inclusive futures for disabled people, Sociology of the Future scholars have yet to engage with the rich, fertile terrain of Disability Studies. For certain, much envisaging of the future is inherently ableist. Disability is a frequent trope for and in dystopias, while more positive or progressive futures ignore the presence and aspirations of disabled people or presume the eradication of impairment in highly technological imaginaries. Disabled people are frequently excluded from individual and collective endeavours to articulate and shape the future. Many disabled people are presumed to lack a future or a future of value, leaving an unoccupied space for existing inequalities and privileges to flourish. This paper interrogates what thinking sociologically about the future(s) can contribute to Disability Studies and how centring disability in these discussions can trouble and enrich futures thinking. In particular this presentation explores the potential of *Futures Literacy* as a method for contesting and resisting disablism and for advancing anti-ableist practices.

Theorizing Disability as a Boundary Object by Combining the Medical, Social and Affirmative

Per Koren Solvang,

Oslo Metropolitan University, OSLO, Norway

Disability Studies scholars have pointed out that the disability concept needs theoretical elaboration. A background for this need is the observation that the disability concept is actively used by justice seeking social movements and welfare state systems but rejected by people with impairments identifying with patient organizations and by people identifying with neurodiversity and comparable diversity proponents. One response to this troubled situation

could be to abolish the concept. Another could be to work on a broad theorization of the concept. This last response is the aim of this paper. The paper outlines an overarching disability theory that includes three frameworks and discuss the potential for the theory to serve as a boundary object for people with impairments, activist organizations, redistributive welfare systems, and scholarly work in disability studies.

In the main part, the three frameworks are outlined. First, the paper elaborates how disability contains ideas about illness, prevention, and cure. These ideas can be perceived both as oppression and empowerment. The paper highlights the empowerment dimension. Second, disability is framed by promotion of social rights and struggles against discrimination. The paper highlights the citizenship rights perspective. Third, a broad disability concept seems to need an understanding of assets pertaining to impairment and peoples' positive identification with being different. The paper highlights the concept of affirmation as a framework encompassing various forms of positive identification with conditions relevant to disability.

The discussion section first elaborates on the potential of the outlined frameworks as discursive powers inherent to a broad and unifying concept of disability. Second, the possible usefulness of such a broad disability concept to diverse actors positioned in heterogeneous social arenas is discussed.

Citizen participation – an ambiguous construction

Monica Larsson,

Lund University, Lund , Sweden

In this paper, an overall understanding of a well-established construction of citizen participation in social work within public authorities is explored. More specifically, the statutory assignments are provided by a contact person according to The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS in Swedish) and a contact person according to the Social Services Act.

The legislation is constructed in partially different ways. LSS is an entitlement law, while the Social Services Act is a law formed as a legal framework with a weaker legal rights structure. The various tasks are ultimately based on the idea of citizen participation in the public sphere, which is about civic engagement, safeguarding human values as well as satisfying democratic interests, and transparency in the activities. In addition, these responsibilities also aim to realize various social policy goals formulated as principles such as empowerment, self-determination, and participation.

This presentation is based on document analysis of preparatory works for legislation, secondary literature and some focus groups and aims to explore how the idea of citizen participation can be understood in relation to these assignments.

Our results show that while the legal construction for the role of the volunteering citizen in these contexts is similar, there are apparent differences in the expectations of the volunteer. Being a contact person for a person with functional impairment has the character of being a friend.

Citizen participation also relates to active citizenship. Legal statuses linked to rights and obligations are included in the concept and practice. The assumptions are that the citizen participates in various sectors of society as citizens are expected to contribute to the

community by doing voluntary work. Our study contributes to understanding the complexity and variation when the common idea of citizen participation is implemented in practice.

11-05-2023

09:45 - 11:05 - **Disability and the Covid-19 pandemic I - Disability in the time of pandemic – lessons from Iceland** ÖBÍ 1 Sigtún 42 /

- Moderator: Ásta Jóhannsdóttir, University of Iceland

- Moderator: Tinna Ólafsdóttir, University of Iceland

Risky Obliviousness Within Fragmented Services: Experiences of Families With Disabled Children During the Covid-19 Pandemic

Hrafnhildur Snæfríðar-og Gunnarsdóttir,

University of Iceland, Reykjavík, Iceland

Living on an island in a pandemic has its obvious advantages. However, in a globalised economy, border restrictions cannot keep the COVID-19 virus completely at bay. Despite coordinated efforts at infection control and extensive vaccination, Iceland, a sparsely populated island in the north, was placed among the countries in the highest risk category by the ECDC. In this article, we report a qualitative study carried out at the peak of the fourth COVID-19 wave in 2021, when the pandemic had severely hit the Icelandic social and healthcare system, with a record-breaking number of infections. Semi-structured interviews were conducted with parents with seven disabled children. Guided by feminist standpoint theory and critical disability studies, we focused on how service structures affected and shaped parents' and children's experiences during the first waves of the pandemic. The findings suggest that the pandemic intensified the already precarious position of the families. During the pandemic, the gaps in the already fragmented services widened, and the families were left to navigate this new reality on their own. Preventive measures enforced by municipalities and healthcare services centred on non-disabled people's experiences and needs. Unprepared service systems distanced themselves from the families while maintaining governance and supervision over defining their need for support.

Consultative processes: Safeguarding disability rights during the COVID-19 crisis

Hrafnhildur Snæfríðar-og Gunnarsdóttir, Laufey Elísabet Löve

University of Iceland, Reykjavík, Iceland

Disabled people's interests have commonly been an afterthought among policy makers and an ad-hoc to existing policy and legislation as key decisions regarding services and rights have been in the hands of non-disabled people. The Convention on the Rights of Disabled People (CRPD) responds to this by obligating state parties to ensure effective participation of disabled people's organizations in the development of laws and policies that concern their interests. In light of past experiences, the CRPD also recognizes the need for heightened vigilance in safeguarding the rights of disabled people during times of crisis.

This study examined how these principles of the CRPD fared during the COVID-19 pandemic in Iceland, a country that has ratified the Convention and written into its core disability legislation an emphasis on the state's obligation to closely consult with DPOs in matters that concern disabled people's interests. Grounded in the critical disability approach and the human rights perspective on disability, the paper draws on the findings of a qualitative research with representatives of Icelandic DPO's conducted in 2020 to 2022.

The findings highlight the important contributions and advocacy of DPOs during the pandemic, as it soon became clear that accessibility issues and the rights of disabled people had not been incorporated into national disaster planning. They played a key role in initiating consultation processes both at state and municipal levels and actively took part in disseminating important information and made it accessible to their members. Drawing on their organizational structure, and close contact with members, DPO's prioritized and addressed problems affecting the everyday life of disabled people, resulting in important actions and amendments. The findings raise critical questions about the degree to which processes of consultation and co-operation have been institutionalized to meet state obligations in accordance with the CRPD.

Loneliness and crip time during the Covid-19 pandemic

Kristín Kjartan Björnsdóttir, Guðrún Valgerður Stefánsdóttir, Ragnar Auður Smára

University of Iceland, Reykjavík, Iceland

For two years Icelanders had to adjust to new and restricted realities of living in the times of a pandemic. While restrictions due to Covid-19 seemed never-ending at the time, people with intellectual disabilities were told or encouraged to shield for longer periods of times. Some are till this day still shielding. All domestic Covid related restrictions were lifted in February 2022, despite high infections rates in Iceland which meant that some people with intellectual disabilities were put at more risk of contracting the virus. In this presentation we will report on qualitative research done with people with intellectual disabilities, their families, and support staff. Our findings demonstrate how people with intellectual disabilities were subjected to more restrictions during the pandemic and how loss of services and shielding led to loneliness and hopelessness among the research participants. Some people with intellectual disabilities were forced to shield during the pandemic due to underlying or pre-existing health conditions while others had to shield to protect the fragile support system, they were reliant on. We will address loneliness and expanded time from a crip time perspective and attempt to explain how their experiences were shaped by notions of ableist time.

Whose lives are worth saving? Changes in discourses in the time of pandemic

Tinna Ólafsdóttir, Ásta Jóhannsdóttir

University of Iceland, Reykjavík, Iceland

During 2020 – 2022 Icelandic authorities employed public protective measures to contain the spread of Covid-19, for example limits on public gatherings, obligatory mask wearing, proximity rules, testing, quarantine, and isolation upon infection. The safeguards were

updated multiple times over the two years, depending on the current infection rate and load on the healthcare system and society at large. Other influencing factors such as economic pressure also played a role.

The aim of this paper is to examine the discourses appearing in media coverage on the response of the Icelandic authorities during the Covid-19 pandemic from 2020-2022. We are particularly interested in how discursive truths about disability and health collide and the effect it has on the disabled population in Iceland.

We collected digital texts in the mainstream media using keywords to find relevant news: Quarantine, isolation, vulnerable groups, risk groups, masks, social distancing, herd immunity, restrictions on public gatherings, shielding, Covid-19, coronavirus. We analyzed the data using Foucauldian discourse analysis (FDA) (Björnsdóttir & Jóhannesson, 2009).

The findings suggest that the authorities tried in the beginning of the pandemic to build a social consensus and group cohesiveness – stressing the importance of the public to follow preventive measures and regulations by the Icelandic authorities and board of infectious disease experts. Changes in discourse over the two years range from fear, uncertainty, and tidbits of solid information on the severity of the pandemic to rely on, to emphasis on solidarity and protection, protecting one another with notions of a war type discourse. However, as the pandemic drags out the third discourse grows more apparent, revolving around freedom of the individual – but only some. Discourse that in the beginning of the pandemic was “us against the virus” becomes “going back to ‘normal’ life” at the expense of those in the so-called vulnerable groups who are left to fend for themselves.

Disabled people in Covid-19 viewed through the lens of relational ethics

Ástríður Stefánsdóttir,

University of Iceland, Reykjavík, Iceland

Disasters like economic crises and pandemics always tend to hit hardest those who are in a marginalized position. It has been shown that poor people, immigrants, homeless people and disabled people generally shoulder a heavier burden than others in this respect. The current Covid-19 epidemic is no exception. Hence, it is important that the ethical framework grounding the planning and decision-making in this epidemic as well as in future epidemics is sensitive to the situation of marginalized groups in society and attention is paid to a fair distribution of the burdens that epidemics impose on us. Ideas from feminist health care ethicists are helpful in this respect. They are grounded in a relational view of the person, using reference to relational autonomy, social justice and relational solidarity. This branch of ethics is useful to detect power imbalance, prejudice and systemic neglect that prevents marginalized groups from accessing necessary services. When using this approach to evaluate ethically the situation of disabled people, the focus is not only on the person but as well on the social environment and the system the person is embedded in. Special attention is on how situations affect their opportunities and status. It focuses on general structures in society leading to oppression and in the case of Covid-19 how these structures influence people's access to health care. This broad perspective where a relational lens is used to analyze ethical issues is especially helpful to reveal systemic discrimination. By using this approach as an ethical framework it is possible to detect systemic flaws that can harm marginalized groups, such as disabled people, and consequently undermine social justice. In this lecture this ethical approach is outlined and applied to evaluate and interpret case examples from the lives of disabled people in the current Covid-19 epidemic.

11-05-2023

11:20 - 12:40 - **Childhood disability I - Caring for a disabled child**

Hilton Nordica meeting room D /

- Moderator: Janikke Solstad Vedeler, Norwegian Social Research, OsloMet

Health of mothers caring for a child with a disability

Idunn Brekke¹, Andreea Alecu²

¹ *Department of childhood and families, Division of Mental and Physical Health, No, Oslo, Norway*

² *Consumption Research Norway, Oslo Metropolitan University, Norway, Oslo, Norway*

Children with disabilities require a great deal of parental investment due to their special needs (e.g. specialized medical care and high numbers of medical visits, organize help and support from multiple siloed agencies), which are frequently greater than those of children without special needs. Mothers often are the primary caregivers, and the intense nature of the care and responsibilities for organizing help and support from different agencies can have an adverse effect on the parents' health, particularly that of the mothers. The aim in this study is to compare the health of mothers who care for a child without a disability to mothers who care for a child with a disability while accounting for the severity of their child's condition. In this study we use Norwegian administrative register data. Our sample consists of first-born children born between 2000 and 2015. We are observing the mothers and their children for 11 years between 2008 and 2019. The outcome variable is mothers' physical and mental health. Mothers' health is measured by using specific diagnoses (ICD-10) in the NPR. Children with disabilities are identified using information on attendance benefits derived from FD-trygd. We differentiate between children that do not receive attendance benefits (children with no disability), children who receive attendance benefits paygrade 1, and children with complex needs, receiving paygrades 2 to 4. Our data is in a longitudinal person-year format. To better understand the substantial implications of our results, we estimate linear probability model. Preliminary results shows that mothers caring for a child with a disability have higher probability of having musculoskeletal disorder, depression and Anxiety compared to mothers caring for a non-disabled child. The differences between the two groups of mothers increase with children's age. Moreover, the differences between the two groups of mothers decrease after adjusting for sociodemographic variables.

Occupational Exposures and Sickness Absence among Mothers of Children with Disability in Norway: A Prospective Cohort Study

Michael Yisfashewa Wondemu¹, Pål Joranger², Åsmund Hermansen³

¹ *Norwegian Social Research, OsloMet, Oslo, Norway*

² *Faculty of Health Sciences, Department of Nursing and Health Promotion, Oslo Me, Oslo, Norway*

³ *Faculty of Social Sciences, Department of Social Work, Child Welfare and Social , Oslo, Norway*

International and Nordic studies have documented that because of their increased caregiving responsibilities, mothers of children with disability reduce their work hours, earn less, and even withdraw from paid jobs. Such demanding caregiving responsibilities can adversely impact their health, resulting in long-term sickness absence. Mothers of children with disability may also be employed in jobs with poor working conditions that have a negative impact on their health. The present paper aims to investigate the effects of occupational mechanical and psychosocial exposures on sickness absence among mothers of children with disability in Norway. We expect that mothers of children with disabilities may have greater levels of long-term sickness absence than mothers of non-disabled children and that such increased risk of absence is affected by mechanical and psychosocial job exposures. Additionally, we expect that the relationship between sickness absences and mechanical and psychosocial job exposures may differ depending on the severity of child disability. Using register data from Statistics Norway, a quasi-experimental design is employed to examine differences in sickness absence by job exposure type. The sample consisted of primipara mothers ($N = 188, 440$), and we controlled for sickness absence two years prior to their children's birth. Preliminary results from the regression models show that mothers of children with disability have significantly higher long-term sickness absence compared to mothers of children without disability. For both groups of mothers, psychological and mechanical job exposures increase long-term sickness absence. There is, however, no difference in occupational exposures between mothers of children with and without disabilities.

Balancing Care and Work When Caring for a Disabled Child

Kaja Østerud¹, Cecilie Anvik², Elena Albertini Fröh³

¹ *Norwegian Social Research, OsloMet, Oslo, Norway*

² *Nord Universitet, Bodø, Norway*

³ *Oslo Metropolitan University, Oslo, Norway*

According to quantitative research on parents, having a disabled or chronically sick child reduces mothers' working hours, income and labour market participation and increases long-term sickness absence (Brekke & Nadim, 2016; Reisel et al., 2020; Wondemu et al., 2022). But how is this apparent conflict experienced, and how does it play out in practice?

This article investigates how caring for a disabled child impacts the participation in paid work. We use a data set following a multiple case study design. We followed 12 families with disabled children over a period of approximately a year. We interviewed the parents on multiple occasions and observed interprofessional meetings concerning the child. In addition, we got permission to interview the family's municipal coordinator, who is responsible for coordinating the support the family receives.

The findings show how the parents, and in particular the mothers, report considerable conflict between care and participation in paid work. This is partially the intensified direct care the child needs, but the families also report considerable effort needed towards fighting the system to get the services and benefits they need. The parents talk about conflict with the workplace and derailed careers. Some of the mothers have left the labour market completely. However, a few of the parents demonstrate how their care work has resulted in

certain strengthened competencies, which they have used as an asset in their search for new career paths.

Unequal access in the universal welfare state? A study of municipal and socioeconomic inequality in the distribution of welfare services for families with disabled children

Vegar Bjørnshagen,

Norwegian Social Research, OsloMet, Oslo, Norway

The Norwegian welfare state includes support arrangements that are available to families with disabled children. Parents may apply for cash benefits provided by the state and welfare services provided by the municipalities. The present study focuses on access to municipal welfare services. While an important principle is that there shall not be social inequality in the distribution services, the outcome of the allocation process is contingent upon parents' negotiations with service providers. Depending on their socioeconomic status, parents' expectations of what is achievable, their ability to navigate bureaucratic processes and their interactions with welfare professionals are likely to differ and affect their success in this endeavour.

Due to the decentralization of the allocation process, outcomes may also depend on the municipal contexts wherein families live. Geographical variation in uptake of services could reflect municipalities' local autonomy with regard to the scope of their service provision, and also differences in municipal characteristics, such as economic conditions and population size. Moreover, the impact of individual-level characteristics of families on uptake may vary across municipal contexts.

To what extent does municipal place of residence influence the uptake of services among families with children with disabilities? Does the impact of socioeconomic status on access to services vary with municipal characteristics? To investigate these questions, the present study uses individual- and municipal-level data from Norwegian administrative registers providing information on all children born in the period from 2008 to 2016 and their parents. The sample is restricted to all children that have been diagnosed with Down syndrome, chromosomal abnormalities, spina bifida, cerebral palsy, congenital heart disease and autism. To investigate the relative variation explained by respectively municipal characteristics and individual-level characteristics, as well as their interaction, multilevel models that retain the information on both the individual and municipal level in the data will be used.

11-05-2023

11:20 - 12:40 - Disability and the lifecourse I - Students with disabilities on the path to the world of work Hilton Nordica meeting room H /

- Moderator: Aud Elisabeth Witsø, NAKU, IPH, NTNU

The story of 14 students in professional higher education and their gatekeepers

Eli Langørgen,

NTNU, Faculty of Medicine and Health Sciences, Trondheim, Norway

This presentation is based on the doctoral dissertation “Disability and professional education in light of experiences of students, teachers, and placement supervisors”. Data was generated through individual interviews with 14 students with various disabilities, and focus groups with 13 teachers and 8 placement supervisors, from 12 bachelor’s programs in pedagogy, social and health sciences. Findings illustrated the importance of making change in higher education, and thus formed the basis for the subsequent studies presented in this session. The students worked hard to be recognized as people with resources to become professional practitioners. Findings revealed complex processes of negotiating an identity as an ordinary student working hard to fit into the normalized expectations in higher education. The students did not want to stand out or be recognized as bothersome, so when facing barriers to their study participation they took a proactive approach to find solutions and to accommodate as best as they could. Coping ‘in silence’, they minimized the disability label and demonstrated capabilities. On their path through education, the students met gatekeepers to the profession – teachers and placement supervisors – who displayed ambivalence towards students with disabilities. This ambivalence seemed to be triggered by unclear qualification indicators, lack of knowledge about disabilities and how to accommodate, time constraints, and insufficient institutional support. The gatekeepers followed up as best they could but were not proactive in meeting students’ challenges. In situations where they had to handle competing demands and dilemmas under circumstances of time pressure and discretionary judgement, the “good” student with disabilities who found solutions and provided their own accommodation was considered as convenient. With the stories of these students as a starting point, this presentation will prompt reflections on how academic success seems to depend more on students’ own resources, and less on formal support from higher education institutions.

Student ambassadors with disabilities strengthen participation and inclusion in higher education

Anita Blakstad Bjørnerås¹, Eli Langørgen², Aud Elisabeth Witsø², Lisbeth Kvam², Ann-Elén Leithaug³, Daniel Myhr⁴, Jenny Marie Ragnhild Andersen⁵, Sissel Horghagen²

¹ NTNU, Trondheim, Norway

² NTNU, Faculty of Medicine and Health Sciences, Trondheim, Norway

³ NTNU, Faculty of Social and Educational Sciences, Trondheim, Norway

⁴ NTNU, Faculty of Engineering Sciences, Trondheim, Norway

⁵ NTNU, Faculty of Natural Sciences, ,

Democratically engaging students with disabilities in co-creating knowledge and actively integrating their experiences and capacities into the co-production of solutions, can be a means to overcome the complex barriers faced throughout education. Despite this, there is a lack of universities actively utilizing students with disabilities in designing relevant solutions for achieving inclusion in higher education.

The ambassador intervention is a research project built on participatory design and action research, where students with disabilities are engaged as ambassadors for promoting change and challenging current structures and power relationships within higher education.

Through this intervention, we have aimed to develop innovative methods for strengthening participation and inclusion in higher education institutions

Student ambassadors have collaborated with researchers and staff at a Norwegian university, where their experiences and voices are utilized and showcased. Through co-creation workshops, students and researchers have worked on understanding the barriers to inclusion that students with disabilities currently face, and have taken subsequent action to address and eliminate these barriers. The student ambassadors have, for instance, shared their knowledge and experiences with new students, developed a checklist for inclusive teaching, attended meetings, and given presentations to university staff.

Preliminary findings from the analysis of workshop recordings and field notes indicate the empowering and transformative value of co-creation. The student ambassadors have discovered that it is the discriminating structures in their surroundings that hinder inclusion, rather than their own bodies. Further, in discovering the power they hold in being able to make changes, they have become translators between students with disabilities and university staff. In this presentation, students involved in the project will share their experiences of being students with disabilities, student ambassadors, and co-creators. They will also share what participation in this project has led to, and where they stand today.

The collaboration forum; Multistakeholders' views on the journey through higher education and onto employment for students with disabilities

Tone Ristad¹, Jørn Østvik², Sissel Horghagen², Aud Elisabeth Witsø³

¹ NTNU, Faculty of Medicine and Health Sciences, Trondheim, Norway

² NTNU, Faculty of Medicine and Health Sciences, ,

³ , ,

The right to equal opportunities in education and work for people with disabilities is widely supported, with over 180 countries having ratified the Convention on the Rights with Disabilities (CRPD). Articles 24 and 27 of the CRPD promote inclusive educational and work environments that are free from discrimination. Still, students with disabilities face barriers in achieving higher education and getting employed. Increased knowledge of these barriers and what counteracts them may promote changes.

In December 2020 - June 2021, The Collaboration Forum was arranged as six workshops that aimed to foster co-learning around obstacles and facilitators for inclusion in higher education and working life for students with disabilities. As numerous types of stakeholders are involved in promoting inclusion for these students, the workshops included participants with a wide spectrum of expertise. Forty-six representatives engaged in the workshops. These included several students with disabilities, as well as a wide range of professionals with relevant knowledge and experience in fields such as education, social services or employment.

Each workshop covered a specific topic, such as procession of information, learning situations, transition to working life, assessment, or attitudes. Introductory sessions and associated discussions in groups and plenary were audio recorded. Recordings were analyzed using techniques from constructivist grounded theory. This presentation will share preliminary findings that illuminate the processes involved in giving and receiving accommodation and adaptations, as well as considerations regarding disclosure.

Perceptions concerning students with disabilities among employees from Norwegian Higher Education institutions and the Norwegian Labour and Welfare Administration

Gemma Goodall¹, Odd Morten Mjølhus², Aud Elisabeth Witsø², Sissel Høghagen²,
Lisbeth Kvam²

¹ NTNU, Faculty of Medicine and Health Sciences, Trondheim, Norway

² , ,

While Norwegian legislation promotes the inclusion of people with disabilities in education and the labour market, individuals are still “othered” in these environments. This can be caused by social barriers, and it is therefore important to build knowledge on how disability is perceived. We studied attitudes towards students with disabilities among employees within higher education (HE) and the Norwegian Labour and Welfare Administration (NAV) through factorial survey experiments and focus group interviews.

A total of 2157 HE- and 1510 NAV-employees participated in two separate surveys that asked respondents to evaluate vignettes describing fictional students. Evaluations involved rating how likely the student would graduate and attain employment, as well as how likely the respondent felt they would be able to assist with facilitation. In addition to disability, factors such as ethnicity, motivation, and disclosure were manipulated across the vignettes in order to assess how the interplay of varying characteristics would affect the respondents' answers.

While attitudes towards facilitating for students with disabilities were reportedly positive, students with disabilities received significantly lower ratings compared to those without when it came to completing education and finding employment. Further, factors such as motivation and disclosure had a significant effect on ratings. Despite this, interaction analyses showed that students with disabilities who possessed desirable characteristics (motivated, extroverted, Norwegian), were oftentimes rated lower compared to students without disabilities who did not possess these characteristics.

Results from the surveys suggest ableist expectations and ideals continue to dominate how students with disabilities are perceived in higher education and employment, despite employees' good intentions. This warrants discussion on how much can be done on individual level, and what ought to be done to combat ableism on a larger, political scale. To provide a deeper understanding of perceptions on this issue, findings from the focus groups will also be shared.

11-05-2023

**11:20 - 12:40 - Deafness I with International Sign Language -
Historical aspects of d/Deafness** Grand Hotel - Háteigur /

Judged as deaf, condemned to silence. The Life Worlds of "Zöglingen" in "Institute for the Deaf and Dumb Linz" and "Kretinenanstalt Salzburg" 1812 - 1869

Lisa Maria Hofer,

JKU Linz, Linz, Austria

This presentation aims to show how different the biographies of students of so-called special pedagogical institutions could look. The research question is: How did these schools construct the phenomenon of disability socio-politically? What supposed social mission did the schools fulfill and in what way? A concrete goal is the intersectional analysis of the socioeconomic conditions of the students: How were the characteristics of gender, class, and disability interrelated during the study period? What interactions resulted for the biographies studied?

The students in the Institute for the Deaf and Dumb in Linz, but also in the Kretinenanstalt in Salzburg, were the target group of private and church efforts. The young people and children were to be made into "useful" members of society. This intention was not covered by uniform legislation and was based purely on the commitment of individual actors who were, however, well networked throughout Europe. Paradoxically, the known source material on the schools under investigation never includes the perspective of the students, but a large body of material deals with the so-called "Zöglingen" from the perspective of the pedagogical staff. Here, mainly master data and pedagogical reports have been preserved.

The article will contain a quantitative and a qualitative part. In a first step, the social and economic environment in Salzburg and Linz in the period under investigation will be presented and the historical relevance of the two examples will be shown. Subsequently, a quantitative survey from "Zöglingenkatalogen" will show how the aforementioned intersectional characteristics affected job prospects and which central role the categorization "blödsinnig" took or which consequence this entailed. The qualitative part of the study traces the careers of three selected students and exemplifies the influence of the teaching methods in the respective institutions on their educational biographies. The path after the institution will also be traced.

NOT A WORD SPOKEN OF SIGN LANGUAGE IN THE SWEDISH PARLIAMENT ON 14 MAY 1981: DISCREPANCIES AND CONTRADICTIONS IN LEGISLATIVE DOCUMENTS ON SIGN LANGUAGE USAGE

Maria Larsdotter¹, Liz Adams Lyngbäck², Stina Ericsson³, Stefan Johansson⁴, Per-Olof Hedvall¹

¹ *Lund University, Lund, Sweden*

² *Stockholm University, Stockholm, Sweden*

³ *University of Gothenburg, Gothenburg, Sweden*

⁴ *KTH, Royal Institute of Technology, Stockholm, Sweden*

Almost everyone agrees on the importance of a strong status of a sign language as the mode of communication for the deaf, and the need of access to public information in sign language. Still - during recent years with a pandemic, international instability and political changes within Sweden, sign language in public information is scarce, unpredictable, or altogether absent.

Sweden is often known for an early acceptance of sign language as the first language of the deaf. Something happened in the Swedish parliament on 14 May 1981, which has later been described as an official recognition of Swedish Sign Language (STS).

However, STS is today not legally regulated in a way that clearly defines certain rights for the users, nor the responsibility for society even though it is mentioned as having a protected status in the Language Act of 2009.

Regardless of a decision having been made in 1983 for STS to be the language of instruction in schools for deaf students, the right to a bilingual education is not granted.

So, what was this 1981 event about and what variations of interpretations can be drawn from it? In this research we have traced the sources of the time and, drawing on Critical Discourse Analysis as presented by Norman Fairclough, analysed what was said regarding sign language within the governmental written documentation in and leading up to the event of 14 May 1981.

The study shows an example of hegemonial negotiation through discursive and intertextual referencing, stalling an actual recognition of STS, and ableist tendencies contributing to this predicament.

Signed Memories research project – ethical questions in interviews and solutions

Maija Koivisto, Hisayo Katsui,

University of Helsinki, Helsinki, Finland

Based on the government program of Prime Minister Antti Rinne, the Finnish government has committed to a state reconciliation process on violations of human rights against deaf people and sign language community in the Finnish history since 1900 to date. As part of this process, our research team was commissioned by the government to conduct a study on the theme.

Research on and with deaf people is not yet well-established and thus it required careful considerations in our study. Particularly we faced Covid-19 pandemic and ethical questions with in-person and group interviews with deaf people. The goal of the research was to bring out sensitive and possibly difficult issues including forced sterilization and abortion.

During the research project, ethical questions were also related to language and interpretation such as the language of interviews and presence of researchers as well as interpreters. The presence of a deaf researcher was also intended to ensure that the wrong kind of power relationship does not arise in interview situations, because a hearing researcher might on an emotional level represent the majority that caused discrimination, injustices and violations of rights to the interviewees, no matter how reflectively the researcher evaluates own role.

11-05-2023

11:20 - 12:40 - **Policy and theoretical perspectives III - Paradigms and conceptualisation 2** Grand Hotel - Gullteigur B /

The political climate in Denmark and views on disability

Pia Ringø,

Aalborg University, Aalborg, Denmark

The way to control and reduce the expenses in the field of psychiatry and disability in the municipalities has, in Denmark, been based on new categories of disability. On the one hand, the reforms are based on decentralization of responsibility by portraying the group of people with disabilities as a group who can, and ought to, develop independence of public services through an abundance of optimism, individual training programs, cognitive skills training, and willingness towards normalization and inclusion; on the other hand, the reforms are based on decentralization of the budgets to the municipalities and a need to deliver more cost-effective services to 'stick to the budgets'. This has led to financial cut-downs in access to specialized services and support and access to diverse societal and institutional settings (Falster and Ringø, 2022). The political, cultural- and moral assumptions about how human beings ought to be capable of being independent have gained significant influence in policy reforms as well as in the frontline practice in the municipalities and user organizations in Denmark. At the same time, the knowledge that investigates the underlying structural mechanisms of society and thereby questions mechanisms, for example, lack of support and accessibility, material deprivation, or societal changes and increased pressure in contemporary civilizations, has to a great extent been marginalized from the political discourse and rhetoric, as well as from the frontline practices (Howe and Ringø 2022). The presentation demonstrates a sometimes less visible historical development and durability in how policy, governance and political ideas of welfare affect the overall view of people and families with disability in the municipalities and how it influences the (lack of) impact of the Convention of Disabled People in practice.

Defining disability in the frontline of the welfare state

Iben Nørup,

Aalborg University, Aalborg Ø, Denmark

Most European welfare states have developed extensive welfare programs aiming at addressing the needs and improving the well-being, life situation, and experiences of inclusion in the society of children and families faced with disabilities. However, when these policies are turned into practice in the frontline, the families often experience that the knowledge they have of their children, as well as family needs and social circumstances, are not recognized. Consequently, they are left feeling unheard when they attempt to make use of the welfare system, especially if their thoughts do not align with the view of the child presented by these professionals, and the result is often that the experienced needs of the families are not met.

Based on extensive both qualitative and quantitative empirical data from surveys, interviews and observations of the frontline, this presentation discusses how frontline professionals' constructions and definitions of disability and what it means for a child or family to have a

disability affect their practice and ultimately, which type of assistance is granted and to whom. The results show first and foremost that disability very often is overlooked or not recognized as something that imposes a risk to wellbeing of the child or family. Secondly, the results show that when disability is recognized is seen as either a problem that is inherent in the child or something that is caused or worsened by a lack of parental abilities in the parents. This means that the focus of the frontline professionals revolves around individualistic solutions which aim at improving either the child's ability to cope or the parental abilities of the parents. Consequently, structural, material, and contextual factors which impact if and to which degree the disability is present are neither recognized nor addressed.

The different positions in studies of neurodiagnoses, and implications for user participation

Camilla Rød Selmer², Anne Hege Strand¹

¹ *Fafo, Oslo, Norway*

² *University of South-Eastern Norway (USN), 3184 Borre, Norway*

There has been an increase in studies of neurodiagnoses as autism, ADHD and tourette over the past few years. This research field is however characterised by different positions towards autism, ADHD and tourette, The positions have however different epistemic foundations, resulting in often conflicting views on user involvement, parental engagement, user participation in research and the role of user organisations.

For example, a distinction is commonly drawn between a psychological position and a neurodiversity paradigm. Where the former is based on an ideal of evidence-based knowledge production with an aim of alleviating suffering of cognitive different minds through medical and behavioural treatments, the latter forms a more 'activistic' position where the 'natural variations in brains' needs to be accepted, and where the voice of users and their needs is at the core of research production.

Others (Stenning & Rosqvist 2021; Bertilsdotter, Rosqvist, Chown & Stenning 2020) point to a possible third position of 'critical neurodiversity' with an aim to reframe or alleviate the medical understandings of neurodiversity defined by clinicians, and to move towards self-representation and social justice.

In this article we look at what characterises different epistemic foundations within the field of neurodiversity. Implications for user involvement and user participation in research is explored with examples from contemporary Norwegian debates on ABA, oxytocin nose spray, and the conduction of a level of living survey among youth and young adults with neurodiagnoses and their parents.

The quest for social citizenship: Exploring the concept of care in the services for young people with disabilities

Wenche Bekken,

Oslo Metropolitan University, Oslo, Norway

How can we understand care in the services for young people with disabilities in transition to adulthood? The tension between independence and support is salient in this phase of life. Empowering the young for the transition take many forms, however, professionals in the habilitation services have responsibility for supporting the young for the new life situation. Social security rights, education, work, and housing are discussed. Aspirations and hope for the life as an adult are topics young people are highly concerned with, however, for the professionals to talk about these aspirations may be difficult. It requires time resources, and it means talking about the challenges regarding future possibilities in education, work, social activities, family, and love.

With the introduction of the concept of care (in the Scandinavian meaning of 'omsorg'), recognition and the distribution of power regarding who's voice is listened to in the planning for the future as an adult, can be more clearly analysed. Care understood as practice, directs attention to what the professionals do, as they try to facilitate for a good start in adult life. A gap may arise between the practices and what the young themselves want to talk about. In the presentation, the experiences of professionals working in the services are used to discuss how the *concept of care* opens for a closer insight about how young people's experiences are recognized. This is relevant in order to improve the services the welfare state provides for this group of young people, and in effect come closer ideal of citizenship for all.

11-05-2023

11:20 - 12:40 - Rehabilitation, technology, and accessibility - Critical rehabilitation studies: Intersections and tensions with disability studies Hilton Nordica - Meeting Room G /

Health equality illuminating the gap between policy goals and rehabilitation efforts in supported accommodations for people with complex mental health needs - Elevating Everyday life

Maria Lindström,

Umeå University, Umeå, Sweden

People with complex mental health needs and impaired autonomy, living in supported accommodations, generally lead sedentary, solitary lives, indoors, and have significantly poorer health than others in the population, while additionally, they do not have access to equal and cost-effective health care, including rehabilitation efforts.

Engagement in everyday activities is important for the recovery towards a meaningful and active life. The person-centered, recovery-, and activity-based intervention-model Everyday Life Rehabilitation (ELR), integrated in supported accommodations, has shown significant outcomes in feasibility studies, and currently an RCT is underway in northern Sweden, for the purpose of establishing the effectiveness of ELR, along with cost-effectiveness, and usefulness. In parallel, qualitative studies and process evaluations are conducted.

Preliminary findings show that the ELR is overall perceived as useful, but experiences also make complex difficulties visible regarding integrated, coordinated rehabilitation and

organizational readiness. Health equity perspectives will be scrutinized in light of policy goals.

Cardiovascular health in people with intellectual disabilities: Rare, forgotten or overlooked?

Linda Oldervoll,

Norwegian University of Science and Technology (NTNU), Bergen, Norway

Background

People with intellectual disabilities (ID) have an increased risk of developing cardiovascular diseases compared to the general population. Despite this enhanced risk, recently published data show that only 8% of people with ID receive medication for cardiovascular problems compared to 17% of the general population. In addition, they are seldom referred to a cardiologist for investigations.

Aim

The objective of this study has been to map the barriers for prevention, investigation and treatment of cardiovascular disease for people with ID.

Material and method

We conducted individual interviews with four general practitioners and six next of kin. In addition, focus group interviews with staff at two rehabilitation centres, one community-based living facility, one obesity outpatient clinic and one cardiac clinic in Norway were conducted. Thematic analysis was used for analysing data.

Results

Our data suggest that cardiovascular problems in people with ID receives little attention. The barriers identified were multifaceted and relate to the organization of the Norwegian health care system, the infrastructure and the work processes concerning people with ID. Insufficient communication was also identified as a barrier in relation to how people with ID often have difficulties expressing symptoms. Finally, a lack of defined responsibility and collaboration as well as culture and attitudes towards people with ID were barriers affecting the prevention, investigation and treatment of cardiovascular disease.

Conclusion

This study shows that several barriers exist relating to the prevention, investigation and treatment of cardiovascular diseases for people with ID. It is necessary in the future to focus on how to improve knowledge and awareness in this field to achieve a more sustainable health service and equalize social inequalities in health for this patient group.

Barriers to and facilitators of health care access of persons with developmental disability: A Systematic Review.

Lily Appoh,

Nord University, Namsos, Norway

International studies show that persons with developmental disability die prematurely, on the average 20 years earlier than their non-disabled peers. Studies have also shown that, factors such as, unmet needs in primary care and diagnostic overshadowing as well as lack of advocacy from carers and service providers health and health literacy issues due to reduced communicative and cognitive abilities are prominent barriers to access to health care for persons with developmental disability. In Norway, persons with developmental disability often receive fewer and poorer health services, compared to the general population and are exposed to specific challenges within the healthcare system.

Good quality data on the use of health services among persons with developmental disability is crucial for informing and planning policies and services that will meet the health care needs of persons with developmental disability. Presently, Norwegian authorities have difficulties in complying with to the UN Convention on the Rights of Persons with Disabilities (CRPD), Article 31 which states that: "The parties undertake to obtain appropriate information, including statistical data and research data, which enable them to design and implement policies that give effect to this Convention." Without such important data, it is difficult to propose effective measures. Accordingly the aim of this review is to analyze and synthesize current knowledge about the barriers to and facilitators of access to care for persons with developmental disability with the view of giving policy makers and health practitioners knowledge base information.

Birth outcomes of parents with disability in Sweden, a national register-based study

Can Liu¹, Ayako Hiyoshi², Fredinah Namatovu³, Mikael Rostila⁴, Alessandra Grotta¹,

¹ *Stockholm University, Stockholm, Sweden*

² *Örebro University, Örebro, Sweden*

³ *Umeå University, Umeå, Sweden*

⁴ *Stockholm University, Stockholm, Sweden*

Background

Birth outcomes of parents with disability remain largely unknown in Sweden.

Methods

By linking national social and birth registers, we analyzed the association between parental disability and adverse birth outcomes. Disability was defined by the receipt of disability compensation in the year before the birth. Of 1,938,876 births during 1998-2016, there were 4221 children born to a mother with disability and 4295 to a father with disability. Poisson regression models were used to compare mothers (or fathers) with disability to their counterparts without disability, adjusting for maternal age and birth order.

Results

Compared to mothers without disability, mothers with disability had an increased risk of gestational diabetes (risk ratio [RR] 1.89, 95% confidence interval [95%CI] 1.55-2.31) and preeclampsia (1.63 [1.43-1.86]). In addition, their babies had an increased risk of low birthweight (1.63 [1.45-1.82]) and preterm birth (1.91 [1.75-2.09]). The association between maternal disability and low birthweight cannot be explained by smoking. Furthermore, maternal weight, measured at first antenatal care visit, was more likely missing among

disabled mothers (1.26 [1.15-1.38]). Less strong but significantly increased risks of the adverse maternal or neonatal outcomes were observed in births to fathers with disability, even when whose pregnant spouse did not have disability (gestational diabetes 1.52 [1.19-1.95], preeclampsia 1.34 [1.14-1.58], low birth weight 1.36 [1.19-1.56], and preterm birth 1.23 [1.09-1.39]). No increased risk of postpartum haemorrhage, post-term birth, or congenital malformation was observed in births to parents with disability.

Conclusion

Births to parents with disability have an increased risk of adverse birth outcomes. Mothers with disability are less likely to be weighed at antenatal care, thereby more likely to have missing data of an important perinatal risk factor. Maternity care practice need to be aware of the health risks and needs of parents with disability.

11-05-2023

11:20 - 12:40 - **Disability and the Covid-19 pandemic I - Critical rehabilitation studies: Intersections and tensions with disability studies** ÖBÍ 1 Sigtún 42 /

- Moderator: Claude Normand, Université du Québec en Outaouais

What has the Covid-19 pandemic meant for the digital participation of people with intellectual disabilities?

Sue Caton¹, Coronavirus and PWL Disability Study Research Team²

¹ *Manchester Metropolitan University, Manchester, United Kingdom*

² , ,

The Coronavirus and People with Learning Disabilities (intellectual disabilities) Study is a UK-wide Study that has been tracking the experiences of people with intellectual disabilities during the Covid-19 pandemic. Data were initially gathered in three waves at different stages of the pandemic during late 2020 to late summer 2021. The study involved interviews with over 500 adults with intellectual disabilities and approximately 300 people with intellectual disabilities were included via family member / paid carer surveys.

The development of interview and survey questions for the study took place through collaboration with people with intellectual disabilities, family carer organisations and policymakers. Through these collaborations, each wave of data collection was adapted to include questions relevant to emerging, urgent issues. The importance of experiences of

using digital platforms emerged as a key issue for people with intellectual disabilities during the pandemic and questions with this focus were incorporated into the study.

The study findings highlighted that people with intellectual disabilities were mostly using the internet for being with family and friends, social media or doing online activities with other people. Best and worst things about using the internet during the pandemic were identified. The experiences of digital participation of people with profound and multiple learning disabilities (PMLD) during the pandemic and beyond was also explored.

Digital inclusion of people with intellectual disabilities during COVID-19: Rapid review and international bricolage

Kristin Alfredsson Ågren¹, Claude Normand², Darren D. Chadwick³, Sue Caton⁴, Esther Chiner⁵, Joanne Danker⁶, Marcos Gómez-Puerta⁵, Vanessa Heitplatz⁷, Stefan Johansson⁸, Esther Murphy⁹, Piotr Plichta¹⁰, Iva Strnadova⁶, Eva Flygare Wallén¹¹

¹ *Linköping University, Norrköping, Sweden*

² *Université du Québec en Outaouais, Gatineau, Canada*

³ *Liverpool John Moores University, Liverpool, United Kingdom*

⁴ *Manchester Metropolitan University, Manchester, United Kingdom*

⁵ *Universidad de Alicante, Alicante, Spain*

⁶ *University of New South Wales, New South Wales, Australia*

⁷ *Dortmund University, Dortmund, Germany*

⁸ *Royal Institute of Technology, Stockholm, Sweden*

⁹ *Trinity College Dublin, Dublin, Ireland*

¹⁰ *The University of Wrocław, Wrocław, Poland*

¹¹ *Karolinska Institutet, Solna, Sweden*

For many people around the globe, the COVID-19 pandemic imposed social isolation and a sudden transfer of everyday activities to the online world. Information and communication technologies (ICT) became essential for social contact, education, work, etc. But not everyone had the same access or opportunities to use ICT to pursue their activities. This presentation describes how this change affected the lives of people with intellectual disabilities (ID) specifically, between 2019-2021.

Researchers from Europe, North America and Australia conducted a rapid review of literature using search terms related to intellectual disability, ICT use and COVID-19. Twenty-seven databases were searched for empirical studies. The authors also contributed to a qualitative bricolage, bringing input from eight countries corresponding to their nationalities. Data from the review and bricolage were analysed thematically.

Results show that living in affluent countries does not prevent people with ID from digital poverty and exclusion. Persons living with ID and their family and support staff experienced a reduction of healthcare and other service provision, greater loneliness and impoverished levels of occupation during the pandemic. Although digital solutions existed, the security concerns and protection imposed by caretakers exacerbated digital exclusion. Lack of digital literacy skills and confidence, sensory impairments and structural barriers also impeded access and use of ICT. However, our review shows that prior experience, adequate finances, support and training for both people with ID and those providing services and support

facilitated digital inclusion. Moreover, this was associated with empowerment, social wellbeing and emotional wellbeing of people with ID during this time.

Evidently, structural barriers, shortcomings and inflexibility were prevalent during the COVID-19 pandemic in organisations, policies and regulations internationally. These may have contributed to digital exclusion of people with ID. Inclusion in the digital world should be considered a human right at this essential time and into the future.

"I would be lost without it but it's not the same" Experiences of Adults with ID Using Information & Communication Technology During the COVID-19 Pandemic

Darren Chadwick¹, Susan Buell², Emma Burgess³, Vince Peters⁴

¹ *University of Liverpool, Liverpool, United Kingdom*

² *University of Dundee, Dundee, United Kingdom*

³ *University of Wolverhampton, Wolverhampton, United Kingdom*

⁴ *Dudley Voices for Choice, Dudley, United Kingdom*

Background: COVID-19 is a life-threatening virus which has circulated the globe resulting in unprecedented effects on the daily lives of people across the world. Countries across the globe have advocated measures, including self-isolation and maintaining social distance to reduce the spread of COVID-19. The pandemic has seen an increase in the use of information and communication technology (ICT) for many aspects of life. This study aimed to find out from people with intellectual disabilities what it was like using ICT during COVID-19 and how this affected their lives.

Method: Interviews and focus groups were conducted with 19 people with learning disabilities throughout the COVID pandemic. The qualitative data gathered was analysed using longitudinal thematic framework analysis to identify the main ways technology use had impacted on people's lives and the challenges and facilitators of technology use during this time.

Findings: Technology played an important role in the lives of the people with learning disabilities who took part in the study. Technology facilitated continuation and maintenance of important daily activities and roles in people's lives (e.g. jobs, getting support and leisure), keeping people meaningfully occupied and maintaining social contact which reduced feelings of loneliness and isolation. People adapted and learned new skills, with help from friends, family and support staff, which boosted self-confidence. Despite some identified barriers, prior technology use, tenacity and a positive attitude towards ICT supported learning new skills and adaptation to increased ICT use.

Conclusions: Supporting the development of digital competence, confidence and persistence in people with learning disabilities was important during this international crisis and has had a fundamental positive effect on wellbeing.

Did people with ID get more digitally included during the COVID-19 pandemic? New data from the survey Swedes with disabilities and the internet 2021

Stefan Johansson¹, Catharina Gustavsson²

¹ *Royal Institute of Technology, Stockholm, Sweden*

² *Uppsala University, Uppsala, Sweden*

The survey contains data from 50 impairment groups and matched controls with the Swedish population. This allows for digital divides to be detected. Data is collected every second year and started in 2017. Data for people with intellectual disability (ID) will be compared to other impairment groups and to the Swedish population without impairment. How was the use of social media, online news consumption, the use of public and commercial online services? Were people with ID able to mitigate the effects of the pandemic by being online?

Sharing digital inclusion experiences and voices of people with intellectual disabilities in Ireland and Sweden with DigiAcademy

Esther Murphy¹, Sara Fiori¹, Orla Shiels¹, Eva Flygare Wallén²

¹ *Trinity College Dublin, Dublin, Ireland*

² *Karolinska Institutet, Östersund, Sweden*

International research has highlighted the issue of digital exclusion among people with intellectual disabilities during the pandemic in a time which requires more than ever their full participation in our digital society.

Lack of digital skills and issue of accessibility compounded challenge of digital access and use among people with intellectual disability was found in our international co creation focus groups.

DigiAcademy is a digital skills e-learning platform delivered via an accessible app by teachers who with intellectual disabilities who have mastered the introductory digital skills education they lead. DigiAcademy co created and co designed with over 300 people with intellectual disability in Europe. It aims to increase knowledge, digital skills and self-efficacy and contribute to increased empowerment and health and well-being for people with intellectual disabilities.

In this paper findings from focus groups with people with mild/moderate intellectual disabilities in Ireland (n=60) and in Sweden (n=50) will be presented to share their experiences of digital inclusion and their input for the design of our app.

11-05-2023

11:20 - 12:40 - **Services I - Policy** Grand Hotel - Huginn /

Organising disability services in Finland. The discussions on rights and individual needs.

Stina Sjöblom¹, Päivi Nurmi-Koikkalainen²

¹ *University of Helsinki / Finnish Institute for Health and Welfare, Helsingfors, Finland*

² *Finnish Institute for Health and Welfare, Helsinki, Finland*

This paper focuses on disability services, in the context of welfare services and disability policy developments in Finland. We look at disability services on a structural level as a means of the welfare state to support the rights and living conditions of persons with disabilities. The period in focus stretches from 2007 when Finland signed the UNCRPD and up until the end of 2021. By examining key policy documents of this time, we explore how disability services are meant to enable inclusion and support independent living and participation in the community.

This paper presents the result of a qualitative analysis of data from a selection of policy documents and grey papers that are considered crucial for the development of social services for people with disabilities in Finland 2007–2021. The data consists of 12 policy documents and grey papers produced or initiated by the Ministry of Social Affairs and Health. The selected documents guide us concerning the development of trends and ideas within the policy context during this period. We conducted a qualitative, theory-driven content analysis of the selected documents examining the emphasis in policy intentions toward inclusion and equality of persons with disabilities.

The analysis of the selected documents highlights the possibilities and challenges in policy developments in Finland. The reformation of legislation on disability services based on individual needs runs parallel with the processes for inclusion and implementing the rights of persons with disabilities in all policies. The intended development of disability services, guided by the ideas of inclusion and equality and explored through policy documents, formulates in three thematic areas: equal rights in society, needs-based individual services, and societal inclusion. We conclude with a discussion on the findings of this study, revealing the need for further actions to address some of the barriers to societal inclusion.

Does individualised funding provide responsive, community- based supports for rural Australians in the National Disability Insurance Scheme?

Kim Bulkeley, Rebecca Barton

University of Sydney, Camperdown, Australi

The National Disability Insurance Scheme (NDIS) was introduced in 2013 as an ambitious public policy initiative championed by the Australian Government to support Australians with a disability to live their best lives. Nearly a decade on, we have been partnering with communities and organisations to understand how to make the most of this quasi-market, individualised funding model for people with disability in rural areas. The rural context brings a complexity to the delivery and sustainability of services and supports that predate the introduction of the NDIS, however, rurality presents an ongoing barrier to achieving the aspirations of this once in a lifetime social policy reform.

Our research has focussed on workforce and service design, including capacity building projects, trauma informed service models, localised workforce models, telepractice, and community development approaches. This presentation will explore insights gained from our stream of research and our engagement with the growing body of literature to build a case that there are threats to the responsiveness and capacity of the NDIS to deliver good outcomes for rural Australians with a disability. The transactional individualised funding approach available to NDIS participants was intended to provide choice and control over the supports that can be purchased, however, in rural areas the impact of this approach on

communities, organisations and the workforce has revealed unintended consequences that threaten the supply and quality of services and support. We will conclude our presentation with some potential adaptations that may ameliorate some of these threats based on listening to and working with communities and service providers.

The ambiguity of idiosyncrasy: the focus on disability in public services

Janne Marita Liaaen ¹, Heidi Pedersen ²,

¹ *Norwegian University of Science and Technology (NTNU), Trondheim, Norway*

² *Norwegian University of Science and Technology (NTNU), Trondheim, Norway*

Aim: In Norway we pride ourselves with practicing following a relational understanding. However, research provides insight into reductionist experiences from service users being in contact with health- and social care services. The aim of this paper presentation is to explore professional practice from a user perspective. We ask whether people with disabilities are being met by professionals using a relational understanding, and if so, what directions are we pulling the relational understanding in?

Method: The data material for this presentation are two separate studies exploring user perspectives of engaging with health- and social care services. The qualitative studies both use semi-structured interviews with service users aged 18-30, all defining themselves as living with disabilities.

Results: Service users experience a one-sided individual focus on impairments, leaving persons feeling placed in less favourable social positions. Service providers focus on criteria for awarding services, thus leading to perceived lack of focus on resources. Resisting this perception by explicating ones' resources and vigour, can cause negative results in that services are denied.

Discussion: From the perspective of the service users, it appears there is conflict between providing information regarding the effects of impairment on everyday life and a need to be perceived as a resourceful and equal person. Perspectives of impairment effects and individual resources are experienced as not being compatible. The findings represent a paradox: the Nordic relational understanding forms the basis for professional practice in Norway, yet individuals experience an overfocus on impairments. Practice reveals a disparity between an idealized form of understanding disability through the Nordic relational model, and the preconditions that guide professional practice.

Children with complex needs in a sectorised service system

Berit Berg, Rebekka Bruteig, Jan Tøssebro

NTNU Social Research, Trondheim, Norway

Norwegian education and welfare services are organized according to sectors (education, child protection, health, social services, etc.), whereas many children/families have complex lives and challenges crossing sector divisions. Several studies have reported that lack of collaboration and fragmented services is experienced as a main problem. This is acknowledged by the government and a recent (2022) legislative reform is intended to combat the fragmentation.

The aim of this paper is a) to discuss to what extent a focus on fragmentation only can remedy the complexities of the challenges families' reports (fragmentation only as opposed to a more wholistic approach), b) to discuss to what extent legislative changes alone can impact the employees' opportunities to meet complex needs, and c) to what extent the legislative changes can trigger more pervasive changes in the way families are met.

The paper is based on qualitative interviews with families and staff in six Norwegian municipalities, and surveys to families and staff in 50 municipalities. Data is gathered as part of the reform evaluation and conducted in phases of reform implementation. The data of this paper addresses the situation when the reform is in its initial phase – a kind of baseline for the reform evaluation. The data will be gathered from November 2022-February 2023, and this paper will present the first results.

The experiences of families and employees will be discussed in relation to theories of street-level bureaucracy and interorganizational complexity.

11-05-2023

11:20 - 12:40 - **Inclusion I - Gender 2** Grand Hotel - Ásgarður /

Pride and shame in queer relationships

Ólafur Snævar Aðalsteinsson, Kristín Björnsdóttir, Ágústa Björnsdóttir

University of Iceland, Reykjavík, Iceland

We will present findings from an inclusive research project about young gay men in search for love and acceptance. Inclusive research is a family of methods where non-disabled and disabled researchers work in collaboration instead of the more traditional hierarchal approach of professional researchers vs. research subjects. The research is on-going and started in autumn 2022. Semi-structured interviews were carried out with six young gay men, three were disabled and three were non-disabled. The young men described the process of telling others about their sexual orientation, their hope for finding love and simultaneously experiencing feelings of pride and shame about their sexualities. These stories are told in resistance to heteronormative and ableist narratives and by telling their stories the young men are carving out space of acceptance. Our inquiry is guided by crip theory which enables us to explain the complex process disabled people are faced with when coming out in a

world that expects them to be compulsory heterosexual or asexual. Finally, we bring the attention to the similarities in the experiences of the non-disabled gay men and disabled gay men who took part in this research. Both have been considered deviant, abnormal, or sick. However, all of them just wanted somebody to love.

Gender, neurodivergence and work: Autistic women's employment experiences in the Canadian context

Isabella Chawrun¹, Ami Tint¹, Bhavnita Mistry², Wanda Deschamps³, Ali Dussault⁴, Corey Hollemeyer⁵, Margaret Spoelstra⁶, Arif Jetha², Monique Gignac², Meng-Chuan Lai¹, Yani Hamdani²

¹ *Centre for Addiction and Mental Health, Toronto, Canada*

² *University of Toronto, Toronto, Canada*

³ *Liberty Co., Toronto, Canada*

⁴ *Auticon Canada, Toronto, Canada*

⁵ , ,

⁶ *Autism Ontario, Toronto, Canada*

Introduction: Sustaining paid work can be challenging for autistic women compared to allistic people and autistic men. Little research exists about autistic women's workplace experiences.

Objectives: We explored autistic women's employment experiences in Ontario, Canada and the intersecting effects of gender, disability, and neurodivergence on these experiences.

Methods: Ten in-depth interviews with autistic women were conducted for this qualitative study. Guided by the research objectives and an intersectional lens, both inductive and deductive approaches to analysis were used. Analysis involved identifying patterns in the transcript data through processes of familiarization, coding, and theme development. Analytic summaries and interpretations were refined at regular intervals with a team of advocates, researchers, and trainees.

Results: Navigating gender and neurotypical norms and expectations in workplaces shaped participants' experiences, which had consequences for their sustained employment and wellbeing. Challenges in work contexts included: adapting to shifts in job roles and responsibilities (e.g., new tasks added to their workload); not noticing and/or not engaging in subtle cultural workplace practices (e.g., multi-tasking during meetings); negotiating and communicating with male supervisors/managers; experiencing discomfort from physical and sensory environments (e.g., fluorescents lights, open concept layouts); feeling overlooked in Equity, Diversity, and Inclusion (EDI) workplace initiatives; and experiencing marginalization and micro-aggressions by colleagues and superiors. Participants also discussed undergoing formal review and conflict management processes, taking extended leave-of-absences, being fired and leaving employment.

Conclusion: This research provides insights into autistic women's employment experiences, and highlights areas where improvements in workplace policies and practices can be made. These include greater attention to making workspaces gender- and neuro-inclusive (e.g., adjustments to physical spaces in sensory-positive ways, fostering collaborative employer-employee relationships) and explicit discussions in EDI workplace initiatives about gender, neurodiversity and mitigating challenges and inequities experienced by autistic women.

How do women with intellectual disabilities view their socio-affective relationships?

Maialen Beltran-Arretxe, Judit Fullana Noell, Maria Pallisera Diaz

Universitat de Girona, Girona, Spain

The affective relationships of women with intellectual disability are characterized by the cultural taboo surrounding them, as well as by the intersectional discrimination of these women. This investigation advocates for researching the intersection between intellectual disability and socio-affective relationships through the voices of women with intellectual disability. The objective of this research is to advance in the knowledge regarding the socio-affective relationships of women with intellectual disability and potentially formulate support strategies and socio-educative programs in the future. To achieve this goal, the researchers carried out a workshop about affective relationships with two groups of women with intellectual disabilities. The workshop sessions were held once a week, each session included a group discussion about the following topics: relationships, gender roles, the LGBTQI+ community, maternity, gender, sexuality, sterilization and abuse. A thematic analysis of the group discussion transcriptions was carried out. The results showed women are interested in talking about their affective relationships, identifying the following themes as the most meaningful for them: couples, support, prejudices, abortion, toxic attitudes, sex education, family, independence and overprotection. This research revealed that the women were aware of the limitations society imposes on them in this area, such as: big external intervention and control from the families, services and society; the lack of specific support; or the prejudices against them, among others. It was also found that knowledge and mutual support networks were created naturally among the participants, and that they found these networks valuable and meaningful. Finally, the women emphasized the necessity of creating specific support services for women with intellectual disability.

Capacity, context, place: an exploration of the lived reality and negotiation of 'capacity' in provider/user dynamics of long-acting reversible contraception (LARC) provision

Rachael Eastham², Alexandra Kaley¹

¹ *Essex University, Colchester, United Kingdom*

² *Lancaster University, Lancaster, United Kingdom*

Long-acting reversible contraception (LARC) are provider-dependent contraceptives that are effective for an extended time period. The UK National Institute for Health and Care Excellence (NICE) have actively encouraged service providers to promote LARC use, and contraception guidelines often cite the 'benefits' of LARC and its use among select populations. Yet uncritical, directive provision can compromise personal choices and reproductive rights, and recent research has exposed research/practice gaps about provision, when individuals are deemed to 'lack capacity' (e.g. learning-disabled people). In this paper we present current research which is seeking to explore the lived reality and negotiation of 'capacity' in provider/user dynamics of LARC provision. Drawing on critical disability studies and feminist theory, this paper shall expand theorisations of 'capacity' from typical biomedical or legal conceptualisations which emphasise individual rationality and an individual deficit model of legal person-hood. We argue that autonomy is achievable only when support, advocacy and enablement are collectively in place, recognising the ways in

which influence is transmitted through webs of connectivity and 'significant others'. Particular attention shall be given to the dynamism and fluidity of capacity, and how it crosscuts people and place, in order to identify how capacity and consent are mobilised in practice with respect to LARC use and provision. We conclude with some reflections on 'new' circumstances and ways in which people might be enabled to exercise autonomy, and how notions of rights and justice are configured, or not, in these spaces.

11-05-2023

11:20 - 12:40 - **Work and employment I - Quality of Employment of People with Disabilities** Hilton Nordica meeting room I /

- Moderator: Sophie Teborg, Federal Institute for Occupational Safety and Health
- Moderator: Lena Hünefeld,

Disability Accommodative Leadership Approaches

Johanna Gustafsson,

Oslo Metropolitan University and Örebro University, Oslo/Örebro, Norway

Unemployment among people with disabilities is higher than among the general population which is affected by both employers' recruitment behavior as well as workplace conditions during employment. Employees with disabilities are at risk for bad treatment from co-workers as well as from managers and supervisors, regardless of whether they have hidden or visible disabilities. Research has drawn attention to inclusion in the workplace; to have both professional and social relationships with other people and thus be included at the workplace, as an important factor for people with disabilities to keep a job. In a "disability-inclusive" work climate, colleagues are more likely to value employees with disabilities as competent and have a supportive behavior towards employees with disabilities. Workplace leadership can thus be a significant factor in creating an inclusive work environment for employees with disabilities. To date, there are few studies on leadership in relation to employees with disabilities, and the knowledge relating to disability inclusion in organizations is uncertain when it comes to inclusive leadership (Gotsis & Grimani, 2016; Luu, 2019) and the perspective of the managers, who are primarily involved in enabling workplace inclusion, is lacking (Maini & Heera, 2019). Accordingly, the aim of this study is to explore inclusive leadership for employees with disabilities. Data was collected in eight semi-structured interviews with Swedish managers in the public sector. Preliminary findings show that the managers proposed four different approaches: *the customizing approach*, *the psychosocial supportive approach*, *the inclusive workplace culture approach* and *the patience growth approach*, which contributed to a disability accommodative leadership targeting workplace inclusion.

How Reflected and Open are Employers in Hiring Decisions regarding Applicants with Disabilities? Results of a Mixed-Methods Study

Frederik Winkelkotte, Michelle Grengel, Hella Sophie Braun, Michéle Möhring

TU Dortmund University, Dortmund, Germany

A major barrier for people with disabilities to find and maintain a job are stigmatizing attitudes of employers. Previous research has shown that particularly lack of knowledge negatively affects the employers' views about productivity, competences, and reliability of people with disabilities (van Beukering et al., 2022). Little is known about the influence of applicant-related (e.g., gender, type of disability) and employer-related factors (e.g., gender, working sector) in hiring decisions. Different studies found evidence for the potential influence of employers' moral values on stigmatizing attitudes (Möhring, 2021). Based on Moral Foundations Theory (Haidt & Joseph, 2004) moral decisions about right and wrong are affected by six distinct moral foundations: care, fairness, and liberty (individualizing foundations), as well as loyalty, authority, and purity (binding foundations). This study includes the influence of employers' individualizing and binding value orientations in hiring decisions.

In an online survey with standardized scales (e.g., Moral Foundations Questionnaire: Graham et al., 2011) and open-ended questions, N = 109 German employers were asked about their perspectives regarding the employment of applicants who face different risks to be excluded from the first labor market (e.g., people with depression, Down Syndrome, or autism). A qualitative content analysis revealed that the employers' argumentations in the hiring process can be distinguished by two dimensions: (1) degree of openness vs. rejection of employment and (2) degree of reflectiveness vs. unreflectiveness in the argumentation. To make these dimensions measurable, the qualitative data was quantified. For this purpose, a detailed codebook was developed, and the data was coded by three independent coders. The resulting quantitative data will be statistically analyzed to investigate the influence of both employer- and applicant-related factors in the hiring process.

This presentation discusses the results and draws implications for research and practice.

The System of Vocational Rehabilitation in Germany – Theoretical Approaches for Innovation and Exnovation

Jan Jochmaring, Bastian Pelka, Jana York

TU Dortmund University, Dortmund, Germany

With the UNCRPD, the German system of vocational rehabilitation is facing an overdue realignment. The political-normative "inclusion pressure" has not yet been adequately met, although legal instruments for creating inclusive work realities are available (Jochmaring 2022).

Alternative forms of employment and inclusion-oriented support instruments - such as the measure Supported Employment, Inclusive Companies and the Budget for Work - remain at a low level without exploiting their development potential. Although there is an overall increase in employment rates, there is no "inclusive opening" in company personnel policy for people with disabilities (Jochmaring/York 2022, BMAS 2021).

The resistance to innovations in the systems of vocational rehabilitation is particularly virulent in the Sheltered Workshop for Disabled People. From a rehabilitation sociological perspective, this can be explained by the organizational inertia (Parsons 2009) of this institution. Despite the legal-normative "inclusion postulate", this segregated system is expanding (BAGüS 2022). The requirement of transition preparation is systematically not

fulfilled and people with disabilities are kept in segregating special systems instead of being placed in the labour market. The “German dilemma” can be seen in the fact that the UNCRPD legally and politically demands inclusion, but the steering logics and instruments of vocational rehabilitation are not geared towards change. An inclusive further development cannot yet be achieved organizationally and it remains with particular vocational substitute offers for people with disabilities (Jochmaring 2022).

We outline elements for the innovation and exnovation of the system of vocational rehabilitation in Germany and discusses the scaling possibilities of inclusive labour market instruments. Established structures and systems that run counter to inclusive work realities - such as existing allocation mechanisms, place quotas, refinancing mechanisms of segregating systems - are examined for their potential for exnovation and levers for change are discussed.

Life-courses, barriers and employment - A longitudinal qualitative study of people with physical disability

Helle Holt, Frederik Thuesen

The Danish center for Social Science Research, DK- 1052 København K, Denmark

In Denmark as in other countries, people with disabilities experience difficulties achieving employment. The last Danish inventory from 2019 shows that 58 percent of persons with disabilities and 84 percent of persons without disabilities have a job. Research has focused on and identified a wide range of barriers confronting persons with disabilities seeing to find a job. Typical barriers are a lack of formal education, discrimination, weak job relevant networks, and low levels of self-efficacy. However, the concept of ‘barriers to employment’ has become so common that it merits itself closer scrutiny. Hence, the aim of the paper is to discuss the use of the concept of *barrier* as a key explanation for the employment difficulties experienced by persons with disabilities. Empirically, we draw on 19 longitudinal qualitative interviews with persons with physical disabilities. The concept of ‘a barrier’ tends to be a static spatial concept. One can overcome a barrier – and then, supposedly, the barrier is eliminated although some barriers, e.g. discrimination, are not easily eliminated and may be internalized by those subjected to its practices. Inspired by Lackoff and Johnsons’ seminal book *Metaphors We Live By*, we argue that the use of the concept of barriers tends to overlook or hide the processes that lead to experienced barriers, and hence inhibits development of adequate processual responses to such barriers. Methodologically, we apply on a life course approach to our interviews to analyze structural and cultural processes that significantly influence experienced barriers among persons with disabilities restraining their possibilities for obtaining education and employment.

11-05-2023

11:20 - 12:40 - Inclusion II - Towards increased user involvement in participatory action research -and co-design processes Grand Hotel - Útgarður /

- Moderator: Lill Hultman, Marie Cederschiöld University
- Moderator: Lars Lindberg, Nordic Welfare Center

The need for user involvement in design and content of services.

Lars Lindberg,

Nordic Welfare Center, Stockholm, Sweden

Empowering users to influence the design and contents of the services they receive has become an increasing priority for the social welfare systems in the Nordic countries. The Nordic Welfare Centre conducted 2021-22 a project about user involvement. The focus was surveying and identifying what models exist in the Nordic countries for user involvement and influence, and their experiences.

In the project, a knowledge compilation of research and experiences has been produced where methods, effects and experiences are described, but also what knowledge gaps exist. Furthermore, how user influence is organized and regulated in the Nordic countries, as well as recommendations for the Nordic countries.

The project shows that there are certain similarities but also differences between the Nordic countries. The most obvious is possibly the extensive work on developing models and strategies for strengthening that takes place in all Nordic countries. However, some patterns can be distinguished, for example that Norway, Sweden and Finland, compared to Denmark and Iceland, seem to have come a long way in the work of creating national initiatives and programs for user involvement both in the health and welfare sector and in research. The results show differences between different concrete investments in different countries. In Norway, for example, a lot of work is done with participant-based research or action research, and in Sweden a close and well-established collaboration between user organizations and various welfare organizations has developed. The results in this report show that studies on user involvement primarily take place through qualitative data collection methods and that many studies focus on investments in influence and participation more generally. A general challenge is that user influence is seen as both an end and a means, and creates ambiguities for how the outcome is to be assessed, as well as on whose terms the user influence is carried out.

The project was coordinated by a project manager at the Nordic Welfare Center. The literature search was carried out by Jens Ineland, Umeå University. A reference group consisting of authorities in the welfare area, user organizations and researchers met seven times digitally. The reference group discussed the results of the literature search and the organization of user influence in each country. To collect supplementary data, two questionnaires were sent, one to researchers and one to authorities. In addition, a webinar was conducted with researchers and organizations. The Nordic Welfare Center compiled the results in a report to the Secretariat of the Nordic Council of Ministers.

Exploration of collaboration and knowledge production.

Lill Hultman, Fredrik Sandman, Jeanette Nelson, Mikael Åkerlund, Lena Von Koch,
Malin Tistad

Karolinska Institutet, Huddinge, Sweden

The aim of this presentation is to share our experiences of collaboration between academic and community researchers in a participatory action research project at Karolinska Institutet.

In this project people with experience of acquired brain injury (ABI) are employed as community researchers. The researchers with experience of ABI are involved in all stages of the research process: developing relevant research focus and questions- project planning- data collection- data analysis and dissemination of results. Analytical autoethnography has helped us to reflect upon our individual and collective research strategies.

After approximately one year of collaboration, we summarized our work so far and identified both barriers and enablers related to: *Start-up and initial challenges, Conditions and structural prerequisites for collaboration, Joint development of work methods and Power and role distribution.*

The results show that the creation of shared resources is necessary for mitigating epistemic injustice and enable mutual learning processes, such as collective writing processes. The results also indicate that full participation for community researchers in the entire research process was difficult to achieve both in relation to structural resources such as allocated time, and perceptions of meaning- making aspects (what one is interested in and what one can contribute with in terms of knowledge). We continuously gained knowledge and developed methods to strengthen our collaboration and reflected upon learning process as well as challenges related to participation in our ongoing research process.

During this presentation we will draw examples from previous studies as well as our ongoing research studies. We will describe and critically reflect upon approaches for collaboration with data collection, analyzing and writing texts as well as the legitimacy of our knowledge production.

User participation in co-design of eHealth – the ‘extreme user’ perspective developed by the research program Co-design for Accessibility (CoDeAc) .

Catharina Gustavsson¹, Stefan Johansson², Joakim Uppsäll Sjögren³, Thomas P Larsson⁴, Thilia Nyberg⁴, Marika Jonsson², Linda Petterson⁵, Mia Larsdotter⁶, Karl Gummesson⁷, Per-Olof Hedvall⁶, Jan Gulliksen², Veronica Milos Nymberg⁸, Lena Von Koch⁹, Ingmar Petersson⁸, Ingrid Demmelmaier¹⁰

¹ Uppsala University, Falun, Sweden, Falun, Sweden

² KTH Royal Institute of Technology, Stockholm, Sweden

³ The Begripsam Group, Stockholm, Sweden

⁴ Funktionsrätt Skåne, Malmö, Sweden

⁵ Centre for Clinical Research Dalarna, Uppsala University, Falun, Sweden

⁶ Faculty of Engineering, Certec, Lund University, Lund, Sweden

⁷ Uppsala University, Falun, Sweden

⁸ Lund University, Lund, Sweden

⁹ Karolinska Institutet, Stockholm, Sweden

¹⁰ Uppsala University, Uppsala, Sweden

The aim of this presentation is to describe how we, as part of the research program *Co-design for Accessibility (CoDeAc)*, have developed methods for accessible and fair user participation by people with impairment in co-design processes.

User participation in the design process, in specific participation of people having such impairments that pose extreme needs of accessibility in the digital design, i.e., ‘extreme

users', is a key to targeting design problems that otherwise will go unsolved and end up in inaccessible and ineffective eHealth. Our rationale is, that by co-designing eHealth services together with 'extreme users', all people will benefit from accessible and usable eHealth. The CoDeAc research program challenge the traditional way of designing eHealth services and wants to develop a model for a reformed design process that emphasizes the 'extreme user' perspective in the development of eHealth.

In this session, we will present how we have applied participatory action research methods for genuine inclusion of the competence and experience of people with impairment in co-design. We will also provide examples of how people with impairment have worked together with researchers, designers and developers. This will show how we have implemented user participation in every step of the design process from early idea-generation to sketching, testing and evaluating complex interactions in prototypes of eHealth services.

The CoDeAc research program has user participation in the research group throughout all stages of the research process: Conception of research question – Project planning – Data collection – Data analysis and interpretation of results. The research group consists of members in the Begripsam group and Funktionsrätt Skåne, whom all have lived experience of impairment, and of researchers that embrace a multitude of perspectives within three main scientific areas: human-computer interaction, design and medicine/health.

Experiences of collaboration with peer researchers with Intellectual Disability (ID) in various roles, based on two studies concerning Agenda 2030 and experiences of pandemic.

Annika Sköld, Eva Flygare Wallén, Ann-Marie Öhrvall, Eric Asaba, Susanne Guidetti

Karolinska Institutet, Huddinge, Sweden

The COVID-19 pandemic has demonstrated the importance of support structures for certain groups such as people with intellectual disabilities (ID). People with ID in Sweden are entitled daily activity services and housing with special services when needed. Daily activity services were reduced in 2/3 of the municipalities in Sweden during the pandemic. Social isolation and difficulties in complying with new rules led to psychological stress and deteriorating health. This emerging knowledge raises challenges, which are further emphasized in the 2030 Agenda. Based on this, our research group is conducting two studies involving peer researchers. **The project aims** to develop knowledge about self-determination in the interaction between people with mild to moderate ID and support persons regarding health and activities, based on experiences from the covid-19 pandemic and knowledge on what kind of support people with ID want to achieve regarding goals in Agenda 2030.

Methods: The project utilizes individual interviews and integrates participatory approaches including both an advisory group of persons with ID as well as persons with ID as peer researchers. Materials from the Easy Reading project are used for cognitive accessibility.

In the seminar, we will 1) describe how to address cognitive accessibility in different parts of the research process. Various methods supporting aspects such as understanding, memory

and reading information and communication will be presented, together with peer researchers experiences of using them. Furthermore, the use of Easy Reading material will be demonstrated and discussed. 2) Researchers' and peer researchers' experiences of being involved in various forms of peer-research will be presented and discussed based on our ongoing studies, where peer-researchers in the first study were specifically involved in the planning of the study and the result discussion. In the second study the peer-researchers participated in all parts of the research process.

Photovoice: Potentiality of dialogue.

Eric Asaba¹, Hanna Gabrielsson², Lill Hultman¹

¹ *Karolinska Institutet, Huddinge, Sweden*

² *Red Cross University, Stockholm, Sweden*

The aim of this presentation is to explore how dialogue can be methodologically understood in photovoice research – particularly in the context of disability research. This can be relevant because photovoice has gained visibility as a relevant approach to engage community members as partners in disability research. However, as methods associated with photovoice have developed and evolved over time, concerns have also been raised about how this impacts the theoretical and methodological underpinnings on which photovoice rests.

Drawing on two empirical studies, the authors reflect on the function and meaning of dialogue, and how this can take different forms within the context of disability research. Examples will include: 1) everyday life experiences of migration and disability from an intersectional perspective drawing on issues such as gender, class, and ethnicity, and 2) everyday life experiences of adults living with spina bifida. It will be argued that the potentiality of dialogue warrants certain reflection to support conditions for participation in disability research. Unpacking the concept of dialogue using potentiality, provides an arena for discussion that has not previously been explicit in photovoice.

11-05-2023

11:20 - 12:40 - Culture and history I - Disability in historical context and contemporary policy ÖBÍ 2 - Sigtún 42 /

Siegfried Braun and the First Austrian Cripple Working Group

Volker Schönwiese ², Angela Wegscheider¹

¹ *Johannes Kepler University Linz, Linz, Austria*

² *Universität Innsbruck, 6020 Innsbruck, Austria*

The history of the early disability rights movements in the 20th century and the resistance of persons with disabilities in the Holocaust is still in its early stages. The Austrian-Czech Siegfried Braun (1893-1944) was a key agent of an early disability advocacy movement and

was active in resistance against the Nazi Regime. Sharing his story can be considered as a “usable past” in understanding the present and building a different future (Longmore 2003).

By using archive material, among other media coverage of Braun and his group in the 1920s and 1930s as well as his diary entries found at Terezín Memorial archive, we managed to reconstruct the diverse, inspiring and long-forgotten story of an early disabled people’s organisation oriented towards emancipation and social rights. The disability activists wanted to move away from being considered objects of charity – a role imposed by the Austrian welfare policy and society.

They actively organised peer counselling, representation, and regular employment in their businesses. From the beginning, the association’s aims were empowering people with disabilities, their claims were employment not pity and employment not asylum.

In the 1930s, Braun maintained an active and reflexive role despite the economically and politically difficult times. He travelled extensively, e.g., through Czechoslovakia, Scandinavia, and Germany. Braun closely followed and documented the development of self-help organisations and public “cripple welfare” in many countries; he wrote about his research findings in the association’s monthly magazine *Der Krüppel* (The Cripple).

In 1943, the Nazi regime deported Siegfried Braun, identified as a Jew, to the Theresienstadt ghetto. Even in the inhospitable environment of the ghetto, he promoted self-help and supported others. Siegfried Braun was described as a “person of importance” in the organisation of the illegal education programme of Theresienstadt. He was murdered in Auschwitz in 1944.

From private to shared memories and identities: Analyzing dialogues between former students at an institution for children with poliomyelitis in Norway

Halvard Vike, Hans A. Hauge, Heidi Haukelien

University of South-Eastern Norway, Porsgrunn, Norway

During the 20th century, many boarding institutions were created to combine education and medical rehabilitation for children with disabilities. They were motivated by optimism for the children’s opportunities to “integrate” (i.e. assimilate) into “normal” society and work life by means of extensive training. They emphasized the strengthening of individual prerequisites for functioning in accordance with existing societal demands. Our research explores how former students in retrospect engage in dialogue on their individualized experiences.

We participated in a 3-days long gathering with structured dialogues between 24 former students at “Linde”, a boarding institution which existed from 1947 to 1987 for children with poliomyelitis. Most participants are now in their 70ies and 80ies. In addition, we conducted in-depth interviews with nine of them. Our aim was to document their memories of experiences at Linde and their assessments of how their subsequent lives were affected. Our analytical approach was based in theories of “memory work” and “semantic extension”.

There is marked variation in the participants’ overall assessment of their experiences from Linde, ranging from “torture” to “salvation”. This variation was evidently surprising to most participants. In dialogues they explored reasons why, and while recognizing differences, they also identified assessments they shared, like not receiving adequate care from employees and experiencing the training as painful. Most participants left Linde seeing themselves as inferior to able-bodied people, and they attributed own achievements in adulthood to a

combination of luck and individual qualities like hardiness. The dialogues nevertheless made them more aware of shared memories and shared identities.

The results from this research has implications for understanding why people with disabilities may find it difficult to develop shared identities, and how such difficulties can be overcome.

Changing policies with women with disabilities: Reflections on More than a Footnote Policy Forum

Deborah Stienstra¹, Bonnie Brayton², Ruvimbo Chidziva³

¹ *University of Guelph, Guelph, Canada*

² *Disabled Women's Network of Canada, Montreal, Canada*

³ *Global Affairs Canada, Ottawa, Canada*

In December 2022, over 100 women with disabilities, policy makers, researchers and representatives of civil society organizations came together in Ottawa, Canada to discuss three critical policy areas and how to address gaps. Many more people engaged through the livestream of the event. The More than a Footnote policy forum was a partnership between DAWN Canada, Engendering Disability-Inclusive Development (EDID-GHDI) and Global Affairs Canada to advance policies and programs that support justice and inclusion for women and girls with disabilities.

The Policy included three moderated panels: 1) Using a livelihoods approach to address childcare, housing and poverty; 2) Gender-based violence; and 3) Canada's international assistance. Each panel included representatives from civil society, research, and government and discussed focused questions. Audience members identified key areas for policy action and strategies for each session. A final report summarizing the outcomes and recommendations was widely shared within policy circles, civil society, and the academic community.

As the co-organizers of the forum, we offer our reflections on the process and outcomes as well as on its success and challenges in bringing concerns of women and girls with disabilities out of the footnotes and into policy and research. We reflect on our intersectional practices and the next steps we imagine for continuing this work.

The right to self-determination of people with disabilities: Challenges to the implementation of the Legal Capacity Reform in Portugal

Paula Campos Pinto¹, Teresa Pinto¹, Patricia Neca¹, Fernando Fontes², Bárbara Maltez¹

¹ *ISCSP - University of Lisbon, Lisboa, Portugal*

² *Universidade de Coimbra, Coimbra, Portugal*

The right of persons with disabilities to self-determination and to the necessary supports for the exercise of their legal capacity has been advanced by Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, and ratified by Portugal in 2009. The CRPD proposes a new conceptualization of disability based on the human rights model and, in the specific domain of recognition of legal capacity, seeks to break with the paradigm of substitution in decision-making, in favor of a new approach based on support for

decision-making, thus appealing to the responsibility of States to remove barriers to full citizenship and participation.

In Portugal, to harmonize national legislation with the CRPD, a new law on Legal Capacity was passed, eliminating the former guardianship regime, which was based on the substitution paradigm. Based on data collected in an ongoing research project, this presentation seeks to sociologically analyze the first years of implementation of this new legislation, whose main goal is to restore the right to legal capacity for all people.

Through the analysis of all legal decisions (N=606) issued over the first two years of the law in three districts of the country, as well as 40 interviews with different actors of this system – judges and court officials, health and rehabilitation experts, staff and leaders of disability organisations, families and people with intellectual and psychosocial disabilities – we discuss the opportunities, but above all, the challenges and arguments that continue to be used to legitimize the exclusion of persons with disabilities from full citizenship.

11-05-2023

11:20 - 12:40 - **Policy and theoretical perspectives II - Identity 2**
Grand Hotel - Gullteigur A /

A World of Indifference?: Living with Learning Disability in the UK

Gareth Thomas,

Cardiff University, Cardiff, United Kingdom

Despite policies designed to improve the lives of people with learning disabilities (LD), they remain at the margins of UK society. They are less likely than those without LD to be in employment and have friendships/sexual relationships. They are more likely to be victims of hate/'mate' crimes, receive minimal provisions in an era of stigmatising welfare reforms, and live in residential settings with low levels of support and reports of abuse. Moreover, health inequalities and avoidable death rates remain stark, and the COVID-19 pandemic only exacerbated the oppression of people with LD.

Confronted by hostile and unforgiving environments, along with assumptions that disability is defined by tragedy and misfortune, people with LD must always justify their value and presence. Frequently excluded from social life and rendered powerless, they are assumed – perpetuated by popular representations – to be miserable and subjects of pity. This

ideological marginalisation violates the experience of being learning-disabled, avoids dismantling prejudices, and pushes people with LD into poorer conditions.

In this talk, I discuss preliminary findings from a qualitative study exploring how adults with LD confront dominant oppressive narratives and articulate their lives in more affirmative terms. Theoretically informed by contributions in sociology, disability studies, and anthropology – and based on ethnographic observations at a theatre company and community café – I capture how adults with LD: 1) reflect upon the external (and problematic) perceptions, stereotypes, and representations of LD; 2) craft alternative identities that recognise their worth and humanity; 3) reflect upon and navigate structural barriers, including modes of activism that confront oppressive regimes stripping people with LD of ‘personhood, care, dignity, and respect’ (Ryan 2020). In so doing, I also show how disability, frequently a niche and overlooked topic in the social sciences and humanities, constitutes a core area of analytic and empirical enquiry.

Living with visual impairments: exploring the white cane and everyday habits

Maria Bäckman,

Stockholm University , Stockholm , Sweden

How do people carry on with previously well-known habits and routines when they are no longer able to fulfil them with the same easiness as earlier? What will one do when the sheer reality, embedded in the body and its declining senses, is working against the everyday habits that up to this point were the backbone of the day?

With these kinds of questions in mind, I have examined the ethnographic material from an ongoing study of the white cane as an aid for persons with visual impairments. Arguing that the idea of someone being blind, visually impaired, or otherwise “disabled”, is a diversified social practice that ought to be thoroughly scrutinised concerning its powerful effects on people's everyday life, and subsequently, with their ways of coping with reality, I will in my presentation discuss the re-orientations that takes place in the informants' own lives.

My point of departure is the ambivalence that many of my informants describe when they inform me about their use of the white cane. However, even though the iconic aid, and its materiality, are in the midst of a complex relationship with the social world, my informants frequently tell me how they perceive, and try to handle, the loss of former capacities. Often these narratives are closely related to anxiety towards an even more troublesome future. Those with a progressive diagnosis know that their still existing visual abilities will gradually become more limited and hence also a greater threat towards ordinary life. Additionally, I will in the presentation also shed light on which new everyday habits and routines they are positioning themselves towards. As life will carry on, one way or another.

'I Don't Dare to Make Changes' the Existential Consequences of Contemporary Austerity Measures for Disabled Swedes

Christine Bylund ,

Umeå university, Umeå, Sweden

Since 2009 a decrease in support for people with disabilities provided by the welfare state has taken place in Sweden (Bylund, 2022; Norberg, 2019). Austerity measures significantly impact disabled people's lives, often resulting in dependency on partners, parents or children or re-institutionalisation (Bylund, 2022).

Previous research has shown that austerity discourse communicated in political debate and media coverage contributes to a discursive idea of disabled people as burdens and counterfeit citizens (Hughes, 2015; Ryan, 2019).

However, in a Nordic context, little research has been produced about how austerity politics impacts everyday life in a practical, emotional, and existential manner. This presentation examines the connections between austerity measures, living conditions and disabled people's existential experiences of themselves, the surrounding society, and their close relationships. It will do so through a crip-theoretical understanding of ableism as a hegemonic discourse that centres the lives and desires of those understood as abled-bodied (Campbell, 2009; McRuer, 2018; Goodley et al., 2014) and a phenomenological understanding of the welfare state as a means of orientation in both material and existential sense producing affects (Ahmed, 2005; Bylund, 2022). Drawing from my PhD thesis and its empirical material of qualitative interviews and autoethnographic writing, the central questions are:

How is the impact of austerity politics in everyday life understood and described by disabled people in contemporary Sweden?

How do austerity politics and the discourses re/produced function as means of orientation to and from everyday actions, sense of self and imagining possibilities?

The presentation will show that media coverage and political debate on austerity measures function as external factors of orientation, presenting specific actions as possible and others as impossible. It also shows that due to austerity politics, disabled people alter their desires, dreams and everyday activities based on changeable understandings of livability and safety.

Children with and without disabilities: Health Promotion and Identity Construction in Norwegian Kindergartens

Ingvild Åmot¹, Borgunn Ytterhus²

¹ *Queen Maud University College, Trondheim, Norway*

² *Norwegian University of Science and Technology, Trondheim, Norway*

This presentation illustrates how the public policy on public health manifests in kindergartens by taking a closer look into the doings and beings of children's everyday life. **Aim:** To show how children create healthy spaces in kindergarten, regardless of their abilities. **Methods:** The study is based on qualitative Constructed Grounded Theory and is carried out in Norwegian kindergartens. The data material has been collected from life-form interviews with 24 children, with and without disabilities in both urban and rural districts; children with enough verbal language to enter into a group dialogue, and when possible, we matched the children with and without disabilities according to age and gender. **Findings:** Children do not talk about health, physical activity, or exercise. They placed health in the context of their daily-life experiences. Children created healthy spaces in kindergarten by focusing on play, interactions, and identity construction as they described everyday routines and daily content.

They described their own engagement in preferred activities and actions and their way of managing their everyday-life to achieve wellbeing. **Analyses:** The children were highlighting the importance of aspiring to social well-being. They described how they related to the staff's restrictions and requirements as "the staff" versus "we, the children". Children who needed help to find positive structures and constructive meanings of / are entitled to individual guidance so they can figure out how to act to be included as a part of the children's we and not as *the other*. As an aspect of health promotion, the children require actions originating on the organizational level where structures open for an increase in the staff's active participation in the children's activities.

Reference:

Åmot, I., Ytterhus, B. Health Promotion and Identity Construction in Norwegian Kindergartens – A Qualitative Study on Children with and without Disabilities. *Early Childhood Educ J* (2022). <https://doi.org/10.1007/s10643-022-01382-7>

11-05-2023

11:20 - 12:40 - **Policy and theoretical perspectives I - Theoretical and conceptual development** Hilton Nordica meeting room F /

The social construction of learning disability; discourses of control, emancipation, and resistance

Melanie Rimmer¹, Cameron Richards²,

¹ *The Open University, Milton Keynes, United Kingdom*

² *Dudley Voices for Choice & The West Midlands Self Advocacy Network, Dudley, United Kingdom*

The preferred term for the group of people currently referred to as people with learning (or intellectual) disabilities changes periodically in a process known as the "euphemism treadmill". As old terms for learning disabilities take on pejorative associations, they are replaced by newer, politer terms. But the new, kinder terms also tend to take on pejorative associations eventually, because the very identity of being learning disabled is often a stigmatised identity. People with learning disabilities themselves, their family members and

advocates, may attempt to resist this stigmatised identity via alternative constructions and counter discourses of learning disability.

Here I report findings from a study into the discourses of learning disability deployed by a range of stakeholders of a Self-Advocacy Group for people with learning disabilities in England. These are groups run by and for people with learning disabilities with the goal of speaking up about the subjects that matter to them and advocating for change. Data were collected from online and physical documents produced by the Self-Advocacy Group, and phone interviews with members and staff of the group, representatives of partner organisations, and other stakeholders. Preliminary analysis focuses on patterns in the way learning disability, and people with learning disabilities, are constructed, and how these differing constructions function to perform a range of social actions. Particular attention is given to concepts of control, emancipation, and resistance.

Persons with profound intellectual and multiple disabilities as subjects of knowledge - exploring the possibilities of empathy

Synne Nese Skarsaune,

VID Specialized University, Bryne, Norway

CRPD states the right to freedom and 'full and effective participation and inclusion in society'. Persons with profound intellectual and multiple disabilities, PIMD, communicating in non-verbal manners, face challenges of being understood. This might lead to their exclusion, others stating on their behalf. Are there ways of getting hold of embodied ways of being, thus positioning persons with PIMD as subjects of knowledge, including them both in research and society?

This brings us to epistemological questions regarding what we can know of another person. There are different views regarding the mind of others, some arguing that such knowledge is primarily inferential. On the other hand, phenomenology offers empathy as a way of experiencing another's subjectivity, not merely imagining it, simulation it, or theorizing about it. Through Edith Stein's phenomenology of empathy, the following is explored;

How does Stein's account of empathy unfold within the context of persons with PIMD?

What are the possibilities of empathy to position persons with PIMD as subjects of knowledge?

Through Stein's account dialoguing with ethnographic material exploring the relation between persons with PIMD and their professionals, it will be suggested that empathy might unfold through acts where the empathizer through embodied communication pours out feelings that create an engagement that the empathized in sensitive ways through perceptive and imaginary resources might receive, feeling into the other.

It is argued that Stein's framework lays the ground for opportunities to position the other as subject, through her insistence on engaging with the particularities of the other in understanding. Furthermore, persons with PIMD demonstrate essential competencies regarding embodied and affective being and relational skills that might initiate an appeal in powerful ways, calling the response of another, thus enhancing the empathic act. Despite the challenges embedded, empathy might contribute to positioning persons as subjects of knowledge.

Managing intellectual disability language in Sweden

Simo Vehmas,

Stockholm University, Stockholm, Sweden

In this presentation, I will analyse the management of intellectual disability language in Sweden. I will focus specifically on the term “flerfunktionsnedsättning” which is the official Swedish equivalent for “Profound intellectual and multiple disabilities” (PIMD). This term reflects how *verbal hygiene* is enacted in Sweden; namely, discourses and practices with an aim to conform language to linguistic, ethical and political ideals. Swedes are very particular about respectful language concerning various minority groups. However, the result of the verbal hygienic process in relation to disability has been the creation of different co-existing vocabularies that often communicate poorly with each other. This is especially the case with “flerfunktionsnedsättning” which is hardly used or even recognized in the field among professionals. I will argue that this terminological confusion is in line, and to some extent, the result of the normative confusion in disability studies and disability policy. In order to clarify such terminological confusion, we have to sort out the related normative confusion as well. Thus, we need to formulate and justify the kind of vocabulary that is accurate and appropriate both in descriptive and evaluative terms. Such analytic process might help us to solve the problem of appropriate disability language.

Depoliticizing Disability - Strengthening the Neoliberal Status Quo. Main Features of the Polish Academic Disability Discourse.

Magda Szarota,

Lancaster University, Lancaster, United Kingdom

"Depoliticizing Disability - Strengthening the Neoliberal Status Quo. Main Features of the Polish Academic Disability Discourse." presentation will map the Polish mainstream academic disability discourse (from 1989 until 2021). This analysis considers how, and to what effect, disability and disability activism have been theorized and researched by Polish well-established disability academics. On the basis of an in-depth analysis, I evidence that the mainstream disability discourse tends to approach disability in an ahistorical and acontextual manner that renders dominant political, economic and cultural discourses 'invisible' and therefore without any influence on the experience of disability. I argue that this is a flaw that legitimizes the processes and discourses which sustain the systematic discrimination of disabled people. Moreover, while scholars of the mainstream disability discourse use the British social model of disability as an important point of reference, they (mis)understand and (mis)apply this model in a reductive manner, which depoliticizes it. The research based on such a reductive understanding of the social model also depoliticizes the sources of the disabled people's discrimination. On the other hand, I evidence that mainstream disability academics avoid theorizing disability in dialogue with a vibrant Polish disability movement which offers important (re)conceptualizations of disability - including

critique of neoliberalism. This presentation is a contribution to international disability studies as the first analysis of the Polish academic disability discourse as well as it also addresses broader questions around the ethos, meaning and effectiveness of disability research within strongly neoliberal (research) systems that scholars are a part of.

11-05-2023

11:20 - 12:40 - **Education I - Higher education and academia 1** Grand Hotel - Muninn /

Rethinking Normalcy: A Case for Anti-Ableism Curricula and Disability Allyship in Schools

Priya Lalvani,

Montclair State University, Montclair, United States

Despite a growing acknowledgement among social justice educators about the need for anti-bias education, issues related to disability justice are not typically taught in schools. Instead, there exists a silence around the topic of disability. This reinforces the idea that disability is irrelevant to nondisabled people, perpetuates stigmas, and allows ableism to go unaddressed. In the USA, some states have mandated that the history and contributions of disabled people be infused in appropriate places within the curriculum. However, there is little understanding or guidance for teachers on *how* to teach students about disability. As a result, students commonly engage in well-intentioned but problematic “disability awareness” activities that aim to put them “in the shoes” of disabled people, but only end up reproducing ableism.

This presentation provides a conceptual understanding of ableism and explicates the multiple ways it plays out in schools. Social justice education is grounded in the tradition of emancipatory or critical pedagogies (Freire, 1972), which emphasize that teaching students to recognize and confront oppression is a fundamental element in bringing change to society. Through critical pedagogies, students can understand the nature of injustices by closely attending to the experiences of others, critically reflecting on one’s own role in injustice, and positioning themselves as agents of change. Based on these theoretical ideas, this presentation invites educators to explore ways to teach students about disability by positioning it as an aspect of human diversity and to question the segregation of people with disabilities in schools and society. Drawing from a disability studies framework, this presentation offers practical strategies, tools, and resources for infusing anti-ableism content within the curriculum and developing models of disability allyship in schools.

Educational quotas and its social consequences: disabled students’ experiences of choosing different accesses to Taiwan’s college admission

Heng-hao Chang, Tong Chen, Fangshan Chang

National Taipei University, New Taipei City, Taiwan

Taiwan's higher education provides special educational quotas for disabled students, but those quotas are limited to certain types of disabilities and academic fields. Accordingly, disabled students have to appear for a segregated Joint College Entrance Exam for Student with Disabilities. They can also participate in the regular college entrance access and apply for accommodations. This research focuses on the social process of applying for colleges of the disabled students. It also addresses high schools' mechanism of supporting such students' decision for college selection, identifying the primary criteria for college selections, and their participation process in college life along with the negotiation of their disability identities. We use quota sampling, and interview 30 first- and second-year disabled college students. This research shows that, disabled students are not encouraged to participate in regular entrance exams, and are encouraged to use the disability special quotas for better schools, despite having limited choices for field selection. Only few elite students choose to participate in regular application processes, in order to select their preferred college majors. After their college admissions, some disabled students indicate a gap between them and other students, despite them being admitted through special quotas. Some chose to hide their disability status in college, due to the social stigma associated with disability and special quotas. Some students also indicate the greater challenges of find appropriate accommodations in college. Hence, this research suggests that, to support students in colleges, we should not only open up quotas for disabled students, but also focus on providing equal opportunities and reasonable accommodations. In addition, the support for disabled students should also address the social and cultural meanings of disabilities, over and above the impairment.

Higher Education and the Reproduction of Ableism: Findings From A Qualitative Study on Factors That Contribute To Disabled University Students Dropping Out

Burgandi Rakoska,

University of Leeds, Leeds, United Kingdom

Background: Modern institutions of higher education were initially created by the elite members of society 'for' the elite members of society (Brabazon, 2015). As such, many disabled students experience unique exclusionary barriers (Dolmage, 2017). Further entangled barriers are experienced by disabled students with intersecting marginalised identities i/e: race, ethnicity, gender, socioeconomic status, sexuality, etc (Annamma, 2016). These barriers contribute to disabled students in the US and UK dropping out.

The Research: In this qualitative study, interviews were conducted by a disabled researcher with disabled students across the US and UK. Each participant dropped out of higher education in some capacity. The social model of disability has been used as the epistemological framework of the study, in order to analyse the ways in which universities, and the broader society, create barriers that contribute to disabled people dropping out. In centring disabled people's voices, this project aims to follow an emancipatory research

paradigm, wherein research is conducted by disabled people 'for' disabled people vis-à-vis "Nothing About Us Without Us".

The Presentation: This presentation highlights themes that have been generated from interviews with disabled people who have dropped out of higher education in the US and UK. In doing so, this presentation showcases examples of higher education contributing to, and indeed reproducing, disabling barriers. These barriers are arguably forms of produced and reproduced ableism, all of which contribute to disabled university students dropping out. Additionally, the presentation highlights suggestions for best practices on how university students can support disabled students.

Blind Perspectives on the Belonging in Academia Model

Laura Yvonne Bulk, Tal Jarus, Laura Nimmon

University of British Columbia, Vancouver, Canada

Blind/partially blind people are underrepresented in postsecondary and lack equitable opportunities to develop a sense of belonging. This study shares narratives from 28 blind/partially blind students from across Turtle Island (what is colonially called North America) using Teng et al.'s (2020) Belonging in Academia Model (BAM) as a conceptual framework. All 28 focus group participants spoke to their experiences as undergraduate students, although some have played additional roles, some multiple: 17 graduate students/alumni, 8 non-academic staff, 7 instructors/adjunct faculty, 4 faculty, and 1 post-doctoral fellow. Thematically analyzed findings suggest blind/partially blind peoples' perspectives offer nuance to the BAM's conceptualization of how belonging develops through affiliation, familiarity, acceptance, interdependent relationships, and sense of equity. *Interdependence* was key to building *trusting connections* for blind/partially blind students, and thus it is suggested the dimension formerly called trusting connections within the BAM be renamed interdependent relationships. Attending to the underrepresented perspectives of blind/partially blind students, stakeholders can become more responsive to the experiences of people from equity-denied groups. Understanding facilitators and barriers to belonging could result in culturally safer practices and more inclusive pedagogical practices. Only when we create a space where *everyone* can belong will higher education move toward being more just and equitable.

11-05-2023

11:20 - 12:40 - **Human rights I - Disability human rights** Grand Hotel - Hvammur /

- Moderator: Inger Marie Lid, VID Specialized University
- Moderator: Rannveig Traustadóttir, University of Iceland

Effective Participation in the International Monitoring of the CRPD?: The Experience of the Disability Movement from Three Case Studies in Europe

Hanxu Liu,

Maastricht University, Maastricht, Netherlands

Echoing the active involvement of persons with disabilities in its drafting history, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides for States Parties' obligations to ensure the participation of Organisations of Persons with Disabilities (OPDs) in relevant national decision-making processes. Following the Convention's ratification, the disability movement's UN engagement has been centring on the international monitoring of the CRPD, and, particularly, made a plentiful contribution to its State reporting procedure. However, existing research paid limited attention to OPDs' effective participation in the UN human rights monitoring mechanisms in connection with the national implementation and monitoring of the Convention. In order to address this gap, this paper aims to examine whether and to what extent national and local OPDs in three case studies of EU Member States - Hungary, Denmark and France – have effectively participated in the CRPD State reporting procedure by reviewing their participation process and results. The case studies presented in the paper draw on legal and qualitative research based on extensive document analysis and in-depth interviews from the perspectives of OPDs, UN experts, and other domestic stakeholders. After introducing theoretical discussions and legal interpretations of the key participatory provisions in the CRPD - Article 4(3) in conjunction with Article 33 - this paper provides a framework for defining, examining and evaluating whether and how OPDs in the case studies have achieved effective participation in the UN monitoring procedure in alignment with the CRPD's principles. Under this normative framework, the empirical results highlight State Parties' obligations derived from the two articles to establish robust national mechanisms for the Convention's implementation and monitoring with OPDs' involvement. This paper discusses the significance of implementing such obligations in facilitating national OPDs' effective participation in the State reporting procedure. Looking beyond the CRPD's scope, the paper further explores the effect of such participation, as reflected in changes in the law, policy and other measures in the respective country's CRPD practice as a (partly) result of the OPDs' participation in the UN monitoring procedure. The paper concludes by identifying contributing factors and main challenges, as well as putting forward changes needed to realise OPDs' rights to participate in the international monitoring of the CRPD and maximise their effectiveness in the context of the EU.

Rights in Crisis: Lived Experience as Knowledge in Policy Development During the Covid- 19 Pandemic

Hrafnhildur Snæfríðar- og Gunnarsdóttir, Laufey Löve,

University of Iceland, Reykjavík, Iceland

The disability human rights approach that the Convention on the Rights of Persons with Disabilities both reflects and represents firmly establishes the right of disabled people and their representative organization to participate in the co-production of laws and policies as a fundamental human right. The Convention's call for disabled people's participation in policy making also includes recognition of the value that knowledge drawn from lived experience of disability provides, thereby deliberately identifying the voices and opinions of disabled people as a key part of the co-production process. Lived experience is recognized as having a place in developing systems, structures and services that are intended to ensure disability rights. Recognizing that the interests and needs of disabled people have commonly been relegated to an afterthought in policy making processes, Article 11 of the Convention specifically highlights the need to maintain vigilance in upholding the rights of disabled people during times of crisis or social turbulence, such as that of war or natural disaster. The unravelling of 'business as usual' during the COVID-19 pandemic, and the need for urgency

in decision making as the crises unfolded, provided a unique opportunity to examine to what extent the rights and needs of disabled people were given attention and weight in the balancing act of decision making under pressure. The research that this paper draws on examined the ability of Icelandic disabled people's organizations (DPOs) to exercise their right to participation in policy making during the pandemic. To that end, the research adopts a disability human rights perspective, in combination with a critical disability approach, to develop an understanding of the extent to which the right to participation and inclusion by DPOs was realized, as well as the organizations' ability to effectively serve as representatives of lived experience in the process. The findings revealed a lack of emphasis by the authorities on ensuring the co-production of policies affecting disabled people and that the rights and needs of disabled people were fully secured. The findings, furthermore, demonstrated the importance of embedding knowledge based on the lived experience of disability in decision making processes in such emergency situations, as well as the differing capacities of the various types of DPOs to funnel this knowledge. The research, which is qualitative, draws on in-depth interviews with representatives of Icelandic DPOs following the COVID-19 pandemic conducted from 2020 to 2022. Interviews were conducted with representatives of established DPOs, impairment-specific disability organization, and grassroots and activist organizations. In addition, document analysis was undertaken of reports and documents pertaining to the issue developed by DPOs and the authorities at the time. The findings emphasize the key contribution of the lived experience of disability in policy development and the importance of developing effective avenues, both within DPOs and at the national, municipal and local levels, to channel this key information into decision making processes.

Painting by Numbers: Disability, Disadvantage and Employment Equity in South Africa

Heléne Combrinck,

Faculty of Law North-West University, South Africa, South Africa

Following the first democratic elections in 1994 and the enactment of the 1996 Constitution, the South African government set out to address the vast chasms of inequality which had arisen from the apartheid regime. The new constitutional dispensation demanded a review of all existing legislation and policies, with the Bill of Rights providing the normative framework for this assessment. It would also be necessary to introduce new legislation to give effect to the spirit of the Constitution. One of these new enactments was the Employment Equity Act 55 of 1998, which contains two distinct parts. The first elaborates on the prohibition of unfair discrimination in section 9 of the Constitution in the context of employment; the second part compels certain employers to take positive steps in the form of affirmative action measures for people from designated groups in order to achieve employment equity. The term "designated groups" refers to black people, women and persons with disabilities. These measures appear to make sense on a formal, one-dimensional level. However, the South African reality is much more complex than the Employment Equity Act may at first glance

suggest and therefore mechanical efforts to comply with the letter of the law may ultimately not yield the intended benefits for persons with disabilities. Accepting that a more nuanced understanding of the intersections of race, gender and disability in the South African context is required, this paper aims to examine disability and disadvantage in respect of employment equity and other measures aimed at accelerating economic participation of marginalized groups. It will interrogate key notions such as “substantive equality” and “empowerment” against the background of a rights-based approach to disability. (This approach is not only mandated by the South African Bill of Rights but also by international instruments such as the UN Convention on the Rights of Persons with Disabilities.) At the same time, the paper will consider how different interpretations of these central concepts may affect the rights of persons with disabilities in South Africa and beyond. The ultimate goal is to reflect on a “transformative equality” approach to disability rights.

Can Disability Rights Flourish Under Illiberalism? – The Case of Hungary

Gabor Petri, Erika Hruskó ,

Central European University, Vienna, Austria

The disabled people’s movement (DPM) has played a key role in advancing disability rights around the world since the 1980s. In the 2000s, the DPM’s participation through their representative organisations shaped the UN CRPD. Today, it seems almost evident that governments ‘must’ consult and ‘meaningfully involve’ disabled people’s organisations (DPOs) in the development of policies and in the implementation and monitoring of the CRPD. The CRPD’s provisions in this regard (Art 4(3) and Art 33) are already part of most inquiries in contemporary disability rights reports – it seems a prerequisite to the successful implementation of the CRPD that DPOs participate meaningfully in policy-making. Yet, recent studies show worrying trends: contemporary governments often take decisive steps to curtail civil society’s influence on laws and policies. This reminds us that the DPM’s participation is always, inextricably linked to States Parties’ broader political issues. The ability to influence policy-making depends on the rule of law, good governance, the state of democratic institutions as well as alliance building tactics, political opportunities and social movement resources. The link between political systems and social movement participation is particularly relevant today when ‘illiberalism’ and populist governments of eroding democracies threaten human rights and their defenders around the world. There is compelling evidence that civil society organisations are facing a ‘shrinking space’ (i.e. Carothers 2016) in a growing number of countries: concerns about attacks on civil society have been raised about Poland, Italy, Russia, Hungary, Slovenia, Croatia, and Serbia (Butler 2017), and a several countries outside Europe. Human rights organisations in general, and groups protecting LGBTQI+ rights, migrants’ rights and feminist organisations are particularly targeted by such attacks. Yet, how DPOs are affected by the erosion of democracies remains largely unknown. In our study, we explored the case of Hungary that has become a ‘poster child’ of illiberalism. Our overall research question was: how has the DPM’s participation in policy-making changed in ‘illiberal’ Hungary? We asked participants to reflect on

government consultations with DPOs, their meaningfulness and how these have changed;

advocacy strategies of DPOs and how these have changed;

changes in the discourse about human rights;

how DPOs perceive the 'shrinking space' concept.

This is a participatory study co-designed and co-executed by a researcher and a disability rights activist with mobility limitation, with over 20 years of experience in advocacy. We interviewed 15 senior disability rights advocates and policy-makers. We also analysed policy documents, including legal texts and civil society statements. Results show a near-consensus that opportunities to influence policy-making have shrunk markedly in the last decade – existing consultative platforms have been weakened and changed. DPOs may self-censor their critical statements fearing repercussions. The meaning of 'human rights' has shifted in public discourse and human rights mechanisms are weakened by this. DPOs have started to change tactics and rely strongly on advocacy strategies that they see carrying less risk. Participants voiced concerns about diminishing inter-disability solidarity and weakening alliances between DPOs, lack of trust and a 'fractured' movement. 'Fear' also featured in several interviews.

11-05-2023

13:30 - 14:10 - Keynote address by Theresia Degener with International Sign Language Grand Hotel - Gullteigur A/B /

11-05-2023

14:25 - 15:45 - Education I - Higher education and academia 2 Grand Hotel - Muninn /

Creating ableism sensitive spaces within the field of academia

Valerie Sophie LIST ,

Bertha von Suttner Privatuniversität St. Pölten, St. Pölten , Austria

Disability and higher education, have according to Dolmage (2017), historically been constructed as two inverse or opposite entities. Through the intermingling of both explicit and implicit expectations, standards and norms and proliferated pressure to achieve or simply to being able, people with disabilities usually don't fit the mold and still often report about sometimes existential troubles to participate at universities. As a legally blind woman I have experienced first-hand what having a disability means at university, the obstacles I had to face and the performative effects the power structure of ableism has asserted on myself and my view on academia. I have come to believe that only by designating the current situation

and explicating the problems at hand, actions towards a more inclusive and ableism sensitive environment at Universities can be taken. This paper presents the first results of my – at time of writing this abstract still ongoing - master's thesis project. In it I have tried to experiment with the idea of *ableism sensitive spaces* within the meritocratic university structure, and in how far such spaces can foster dialogue between students, academic and administrative personal alike. In an iterative fashion, I have co-created a variety of different forms, from group conversations to other more creative approaches where people were invited to express what ableism means to them, how they have been affected by it and what experiences they have made within the framework of academia. In my presentation, I will talk about the settings created as well as their theoretical deliberations. I will show in how far these spaces have led – on an individual and collective level - to show vulnerability, open up, become more aware and empathic about the subtle micro-expressions of ableism and thus reach a deeper understanding of the impact and mechanisms at work.

On Pace and Perseverance: Exploring PhD Supervisors' Conception of Disability in Academia

Karoline V. Rhein, Jana F. Bauer, Susanne Groth, Mathilde Niehaus

University of Cologne, Cologne, Germany

Despite universities' stated commitment to disability inclusion in academia, access to a career in science remains difficult for early-career researchers with disabilities (Bauer, Niehaus, Groth, & Kaul, 2016). In this regard, PhD supervisors have considerable power as gatekeepers. They decide who gets the opportunity to pursue a PhD and influence what resources are available to their PhD students. In this way, they contribute significantly to facilitating or preventing access to academia for researchers with disabilities.

As previous studies have shown, explicit and implicit expectations and perspectives are significant factors in initiating and shaping the relationship between students and supervisors (Grant, 1999). Therefore, unconscious bias and prejudice regarding disabilities in academia may become a key barrier for early-career researchers with disabilities. However, previous research seems to focus primarily on the experiences of disabled academics (Brown & Leigh, 2020; Dolmage, 2017) while the perspectives of doctoral supervisors have rarely been taken into account.

Therefore, we conducted semi-structured interviews with doctoral supervisors of disabled PhD students ($N=22$) as part of the project "PROMI – promoting inclusive doctoral studies". The aim was to explore how supervisors conceptualize science and, on this basis, make statements about disability in academia.

The initial results of the analysis show the complexity of the topic. On the one hand, the majority of interviewees report positively on their own experiences supervising PhD students with disabilities. On the other hand, they often maintain a critical perspective on the compatibility of disability and academia. They argue that, for example, disability-related time expenditures and the additional work of bureaucratic processing of accommodations are sometimes incompatible with the pressure of PhD life.

A goal of further research should thus be to identify institutional approaches to inclusivity that reduce the challenge for PhD students and support PhD supervisors in their key role in academic careers.

University students with disabilities' experiences in accessing the university-built environment in Zimbabwe: A New Materialist perspective.

Vitalis Bengano¹, Edurne García Iriarte², Michael Feely²

¹ *Trinity College Dublin, the University of Dublin, Dublin, Ireland*

² *Trinity College Dublin, Dublin, Ireland*

The Convention on the Rights of Persons with Disabilities (CRPD) of 2006 is acknowledged as the global human rights instrument guiding state parties in addressing disability issues. Besides the explicit recognition of accessibility in articles 3 and 9 of the CRPD, it is axiomatic that the realisation of a myriad of human rights by disabled people is effectively dependent upon the accessibility of the built environment (Jackson, 2018:8; Devandas-Aguilar, 2016). However, the existing built environment is still considered inaccessible to disabled people globally (Jackson, 2018:1; Tudzi, Bugri and Danso, 2017). This problem is considered to be more severe in the global south (Aldersey et al., 2018:25; Trani and Loeb, 2010). Despite the reported upward global trends regarding the admission of disabled students in higher education, research suggests that they continue to experience multiple violations of their rights within the institutions that admit them (Abuya and Githinji, 2021:1). However, there is a noteworthy dearth of empirical evidence of human rights violations based on the built environment in higher education in the global south. Experimenting with a theoretical framework borrowed from Deleuze and Guattari (1987) of Assemblage analysis, this study explores the material/discursive processes mutually affecting the capacity of disabled students to access the built environment in a higher education setting in Zimbabwe, a global south context. This presentation will focus on a review of the literature on this issue and the exploration of how New materialism and qualitative research provides a relevant framework and methodological approach to understand the experience of accessibility more comprehensively. This study is envisaged to engender a contextualised understanding of existing processes that facilitate access to the built environment among disabled students in higher education. Findings are anticipated to support evidence-based decision-making in the provision of accessible higher education-built environments in a global south context (Zimbabwe).

Studying with invisible impairments - a closer look at the (non-)disclosure decision in the context of higher education

Jana Felicitas Bauer¹, Yvonne Kirsch², Mathilde Niehaus¹

¹ *University of Cologne, Cologne, Germany*

² *Stiftung die gute Hand, Cologne, Germany*

Eleven percent of German university students live with at least one impairment that affects their studies. Most of these impairments (96%) are not immediately apparent to others, and 67% stay invisible even in the long run (Poskowsky et al., 2018). University students with invisible impairments are in the unique situation that they can decide whether, when, and how to disclose their impairment or aspects of it to others. For many, this decision is a dilemma. While at least some degree of disclosure is necessary to claim disability-related rights (like reasonable accommodations) and to receive support from fellow students and faculty, possible negative consequences are being confronted with prejudice and stigmatization. Thus, in the present study, we aimed to explore how university students with

invisible impairments navigate this decision to identify starting points for tailored support. We invited German university students with invisible impairments to participate in an online survey on their (non-)disclosure decision, reasonable accommodations, and disability-related study experiences. $N = 361$ students from various universities and disciplines at different stages of their studies with diverse impairments completed the questionnaire. Nearly half of the participants (45%) experienced rather heavy or very heavy disability-related constraints in their studies. While 68% had disclosed (aspects of) their impairment to at least one person (primarily fellow students or faculty), 39% had told nobody at their university anything about their impairment. The study sheds light on the motives for and the positive and negative consequences of (non-)disclosure. It also shows that many participants (especially those who have not disclosed) do not know what reasonable accommodations are. Thus informing students with invisible impairments about their rights, raising awareness of fellow students and faculty, and creating a supportive environment that facilitates disclosure are pivotal for fostering inclusion and equal opportunities in higher education.

11-05-2023

14:25 - 15:45 - **Policy and theoretical perspectives I - Social policy and independent living** Hilton Nordica meeting room F /

A lost promise? Assessing the implementation of social protection standards for persons with disabilities in Morocco and Tunisia after the Arab Spring

Teresa Janela Pinto,

ISCSP, University of Lisbon, Lisbon, Portugal

The Arab Spring brought to the forefront of the political scene claims for democratic reform and for more effective and inclusive social protection systems in the Middle East and North Africa. In Morocco and Tunisia, persons with disabilities and their organisations, were actively involved in these protests, and in the ensuing efforts to materialise those claims in a reformist agenda. At the core of these claims, was the quest for social protection reforms, compliant with international human-rights standards.

Social protection standards set by the CRPD, particularly in article 28, and clarified in subsequent documents (e.g., ILO & IDA, 2019), advocate for a dual-path approach encompassing accessible services, non-discriminatory provisions, and facilitated access to contributory and non-contributory programmes, to address the complex interplay between disability, poverty, and social exclusion. Persons with disabilities tend to incur in extra costs, both direct and indirect (Mitra et al., 2017), which compounded with other structural and institutional factors, may place them in higher risk of poverty and social exclusion (Banks et al., 2017; Palmer, 2013). In Morocco and Tunisia, the multidimensional nature of deprivation faced by persons with disabilities has been shown to place them in higher risk of poverty and social exclusion (Trani et al., 2015).

This paper will present the results of a study conducted in the region using a multi-method approach. Through an analysis of laws and policies, surveys, and semi-structured interviews with persons with disabilities in Morocco and Tunisia (n=120) we assess how international social protection standards for persons with disabilities have been translated from principle to practice, and state key lessons regarding the role of structural, institutional, and procedural barriers in the implementation of disability rights standards in the aftermath of the Arab Spring.

Persistence and a shared framework - the long way to ensure disability rights in Switzerland

Elisa Fiala,

Lucerne University of Applied Sciences and Arts, Lucerne, Switzerland

Switzerland is undoubtedly one of the richest countries in the world. It also inherits the most extensive elements of direct democracy amongst the world's democratic states. One would think that therefore human rights of Swiss citizens are quite protected. This is however not the case if you belong to the Swiss disabled population. Although Switzerland has ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2014, the latest monitoring cycle shows that Switzerland still has a long way to go to ensure that the rights of its disabled citizens are protected and enforced.

Focusing on the area of independent living the paper outlines the ongoing obstacles people with disabilities experience in their everyday lives. Based on a policy review it will be shown how policies and jurisdictions in place hinder full social participation of disabled people and strengthen institutionalisation instead. While inhabiting less than 9 million people (1.8 million living with a disability), there are four official Swiss languages (sign language not being one of them) and the country consists of 26 independent cantons. In all 26 cantons there is an independent disability legislation in place. The paper argues that the so called "Kantönlisgeist" (cantonal provincialism) can be seen as one of the main obstacles for disabled people's full social participation and it also makes alliances more difficult. Despite all obstacles there recently have been few legislative changes showing that persistence can be seen as a key to change and abolish discriminative policies in place. Within this process the CRPD has been a framework that ensures that despite all regional and cantonal differences a common language – that is based on human rights – is spoken.

Institutionalized housing for people with disabilities?

Anthon Sand Jørgensen,

Via University College , Viborg, Denmark

A quantitative nationwide study of housing for adults with intellectual disabilities indicates that institutionalized settings still exist to some extent or that re-institutionalization is again trending in Denmark.

The study is conducted on the basis of register data from the Ministry of Social Affairs in Denmark and self-produced geo-data. The study documents that there are approx. 15.800 apartments for adults with intellectual disabilities in Denmark. According to register data, approx. 12 apartments are placed together per department on average. But if instead, you are geo-mapping the departments, placed within 100 meters, there will be approx. 19 apartments placed together on average. Furthermore, register data approximates that one in five adult residents with intellectual disabilities lives in department facilities with 30 other residents or more. But by geo-mapping, the departments placed within 100 meters, nearly every second resident lives together with 30 others or more. Despite this, approx. 68% of all apartments for adults with intellectual disabilities are formally the resident's own homes with a separate lease contract.

The study may raise concerns about whether adults with intellectual disabilities actually live independently and are included in society or whether institutionalization continues /exists in Denmark again. Studies indicate that large institutions often take on the character of a workplace for the staff and look less like a home for the residents. Furthermore, several studies unequivocally point to the fact that residents with intellectual disabilities benefit positively from community living as opposed to living in institutionalized settings. Based on the study's documentation of the current housing situation for adults with intellectual disabilities, more research on how care and support are provided is needed in Denmark. Furthermore, this study hopefully contributes to a discussion about housing and institutionalized care for people with disabilities in an international context.

An unentitled life: The lived experiences of residents in supported housing for people with psychosocial disabilities with regards to independent living

Katla Stefánsdóttir,

Háskóli Íslands, Reykjavík, Iceland

The aim of this qualitative study was to gain comprehensive knowledge and understanding of the lived experiences of residents in supported housing for people with psychosocial disabilities with regards to independent living, and how intersecting factors such as past experiences and internalized ableism have a formative effect on that experience. The research was conducted according to Charmaz' social constructivist grounded theory. In addition, a critical disability theory perspective was applied to the data analysis. The participants were 12 residents in supported housing in the city of Reykjavík. They had all been diagnosed with schizophrenia or bipolar disorder. The findings revealed various intersecting factors that had an inhibiting effect on residents' possibilities for independent living as their options were structured in such a way that they had none. Within the supported housing, other people's perspectives and attitudes guided their lives through rules and agreements, and they had limited opportunities to determine their own lifestyle. The residents' understanding of independent living was not consistent with the definitions of the CRPD and the ideology of independent living. Together with a lack of knowledge about their

rights and the services they were entitled to, this made the residents dependent on the decisions of professionals and service providers when it came to most aspects of their lives. Intersecting effects of past experiences, internalized ableism and other diverse factors had a formative effect on the demands the residents made of their life. They believed they were flawed and inferior to other people and not entitled to independent living. Therefore, they accepted their place of residency where they experienced safety, freedom and stability compared to their previous lives of illness, psychiatric wards and insecurity.

11-05-2023

14:25 - 15:45 - **Childhood disability I - Caring for a disabled child**
Hilton Nordica meeting room D /

- Moderator: Janikke Solstad Vedeler, Norwegian Social Research, OsloMet

Medical cannabis treatment for children with Autism: benefits and barriers for parents and family

Ayelet David¹, Naomi Schreuer², Eynat Gal¹, Orit Stolar¹

¹ *University of Haifa, Haifa, Israel, Haifa, Israel*

² , ,

Autism spectrum disorder is a developmental disability associated with a decrease in daily functioning and participation. Caring for autistic children is fraught with serious challenges influencing not only the child, but also his family.

Cannabis treatment for autistic children has become popular in recent years. To date, studies have focused on examining its effect mostly on the child, and little is known regarding benefits and barriers for the whole family, and how these impact access and use of the treatment for the disabled child. This mixed-methods study aimed to examine (1) the effect of medical cannabis on parental well-being and on Family Accommodation (FA), and (2) parents' perspectives regarding the benefits and barriers of this treatment for both the child and family. We analyzed data for 44 children (5–12 years old) who participated in research regarding the effect of medical cannabis on autistic children. Following completion of the treatment, 15 parents of children from the full sample participated in in-depth interviews.

Results indicated a significant decrease in FA after three months of treatment. Subsequent interviews indicated positive changes in the family's routine and sense of well-being. Parents' ability to engage in meaningful occupations and enhanced interactions with family and friends were increased following the intervention, due to decrease in the child's maladaptive behaviors and in FA required. Although we found this treatment to have a relatively high adherent rate, treatment wasn't free of barriers. The medical cannabis intake regime, maintaining treatment sequence within the community, high cost, accessing treatment following the study, and dealing with the legal aspects of this treatment have been reported as challenging.

Results both support the effectiveness of medical cannabis treatment for ASD and highlight the burden imposed on parents and their need for welfare and professional support to ensure access to appropriate services.

The experiences and meaning of using MyTime in the preschool context from the perspective of children in need of special support 5-6 years of age

Sara Wallin Ahlström¹, Lena Almqvist¹, Gunnel Janeslätt², Catharina Gustavsson³, Maria Harder⁴

¹ *Mälardalen University, Center for Clinical Research, Falun, Sweden*

² *Gunnel Janeslätt Centre for Clinical Research Dalarna, Region Dalarna, Sweden, Falun, Sweden*

³ *Center for Clinical Research Dalarna, Health and Welfare, Dalarna University, Fal, Falun,*

⁴ *Mälardalen University, Västerås,*

Background: MyTime is an intervention program for systematic training of Time Processing Ability. Children in need of special support often display delays in time-processing ability affecting everyday functioning. MyTime shows positive effects on Time Processing Ability for older children in special schools. A previous study shows that MyTime is suitable with children in the preschool setting. Yet, there is a lack of knowledge regarding the preschool children's own experiences and meanings of using the intervention programme. This is of great value for further development and integration of MyTime in the preschool setting. The aim of this study was to explore the experiences and the meaning of using *MyTime* from the perspective of children INS 5-6 years of age in the preschool context.

Methods: To explore the children's perspectives a Hermeneutic design was used. Video recorded interviews from 21 children were analysed. To facilitate the interview situation with the children in need of special support the Talking Mats® was used. Both body and spoken language were analysed.

Results: The results reveal children as active participants, willing to share their experiences of using the intervention MyTime in the preschool context. The conceptualisation of the children's experiences and expressions uncover their meaning of using the intervention MyTime as: To know and to understand time by doing.

Conclusions: When children are given the opportunity to use concrete tools to understand and measure time, they experience themselves as active participants involved and engaged in the intervention. They reveal meaningful experiences to be able to manage time that facilitate their everyday functioning and participation in the preschool context. The children's perspective of MyTime as a program concretizing time in relation to activities can assist preschool teachers, occupational therapists as well as parents to support the children to develop abilities in TPA useful for their everyday functioning.

Family as infrastructure for persons with intellectual disabilities

Jenny Frogner,

NTNU, Trondheim, Norway

Parents of children with disabilities in Norway put in considerable time and effort to care for their children and interact with service providers. While this also appears to be the case when children with intellectual disabilities (ID) reach adulthood, the relationships between adults with ID and their family members in the Norwegian context are to a large extent unexplored by research.

Based on data from ethnographic fieldwork, this paper explores the relationships between adults with ID and their parents using the concept of infrastructure. Participant observation was conducted in the everyday lives of adults with ID, taking the individual rather than particular sectors of society as a point of departure, to facilitate an understanding of social relations that span across different life areas and of how such different life areas might be interconnected.

According to Larkin (2013), infrastructures “facilitate the flow of goods, people, or ideas and allow for their exchange over space”(328), they are “things and also the relation between things”(329), and they can be technological systems, financial instruments, management systems and organizational techniques, or biological or social structures. In the article “People as infrastructure,” Simone (2004) shows how the activities of some persons serve as infrastructures for the activities of other persons in settings with limited institutional support. Inspired by the idea of “people as infrastructure,” this paper argues that family relations can be understood as infrastructures for the agency of persons with intellectual disabilities.

11-05-2023

14:25 - 15:45 - **Inclusion II - Political participation, advocacy and voice** Grand Hotel - Útgarður /

From Self Advocate to Legislative Advocate, through Inclusive Research

Fionn Crombie Angus¹, Jonathan Angus²

¹ *Fionnathan Productions, Galway , Ireland*

² *Fionnathan Productions, Galway, Ireland*

As a non-traditional researcher with living experience of Down syndrome, Fionn's research interests begin with exploration of his own life. Lessons learned through his Happiness Project, made up of 600 filmed interviews asking people 'What do you love about your life?' guide his own life choices.

He was approached in 2021 to help establish the National Down Syndrome Policy Group (NDSPG) in the UK, even though he is Irish. Their primary goal was to develop and shepherd Down syndrome-specific legislation. He agreed, on the condition that he could focus his efforts on research.

He helped establish the Advisory Group for NDSPG concurrent with his work establishing IASSIDD's newest Special Interest Research Group (SIRG) on the theme of Inclusive Research, and was eventually asked to chair both groups (with assistance from his father / research partner). As a SIRG chair, he was appointed to IASSIDD's Governance Committee, the first person with intellectual disability in the organisation's history.

He has since been awarded IASSIDD's Achievement Award for Service to the Community.

The NDSPG was incredibly successful: with the Down Syndrome Act passed just one year later (April 2022). Fionn was chosen, among the five Founding Officers with Down syndrome, to give a Parliamentary address on World Down Syndrome Day.

The Advisory Group is nearly 40 people with Down syndrome, and Fionn, with training and experience leading focus groups for the Inclusive Research Network of Ireland, was asked to run two such groups, in London and Leeds, for the UK Department of Health's stakeholder consultation process.

Fionn's goals now are to help bring similar legislation to his home country, and to serve an internship at the European Commission, European Parliament or United Nations.

This presentation will share a journey from self advocacy to legislative advocacy, by way of inclusive research.

Ecoar - Citizenship Dialogues: A project for the popularization of science and social empowerment at the interface between information, communication, and culture

Cristina Rabelais , Daniele Novaes, Tuca Munhoz, Maria Fernanda Bittencourt

Fundação Oswaldo Cruz and UNIFASE, Petrópolis/RJ, Brazil

In Portuguese, the verb "ecoar" means to echo or reverberate. This is an experience report of a communicational, informational-cultural project intended to build more effective connections between society and the academy, translating knowledge and academic reflections into accessible language, favoring the appropriation by ordinary citizens, and enabling some citizenship construction.

Ecoar aims at promoting information about people with disabilities. Respecting social movements and citizens as protagonists of the struggling for their identities recognition and rights, the interview program is conducted by an interviewer with a disability, a human-rights activist, and a consultant specialized in accessibility. It is, in general, addressed to three interviewees, alternating people with and without disabilities, specialists, and lay people, and it approaches issues related to citizenship and human rights in a friendly and relaxed way.

There have been eleven episodes up to November, simultaneously broadcasted on the YouTube channel of VideoSaude of Fiocruz and on UNIFASE's channel. The themes covered included masculinity, education, mobility, inclusion, and violence, having ableism as the transversal theme. The episodes have had more than 2500 views so far.

Ecoar aims to popularize science, understanding that translation and democratization of scientific knowledge are tools to promote citizenship, empowering citizens to participate in decision-making about public policies. Carried out by institutions that work in the formation of human resources in health, Ecoar seeks to sensitize students to commit themselves to the construction of a fairer and more respectful society with citizens, besides caring for the biological body affairs of patients.

Ecoar is supported by the project SISDEF - National Information System on Disability, carried out under a collaboration agreement TED 01/2020, signed between the National Secretariat of the Rights of Persons with Disabilities (SNDPD/MMFDH) and the Institute of Communication and Scientific and Technological Information in Health (ICICT/Fiocruz), under the general coordination of NIPPIS/Fiocruz&UNIFASE.

Influence and participation of young adults who have an intellectual disability, in the local community's social arenas and democratic processes

Jenny Rosendahl, Mara Westling Allodi, Jenny Wilder

Stockholms universitet, Stockholm, Sweden

To achieve citizenship, all citizens need to be able to make their voices heard. Policy and practice in the welfare society stress that all citizens should be included, but in reality, young adults who have intellectual disabilities (ID) are often excluded.

The aim was to study how young adults who have ID acquired citizenship and how young adults who have ID experienced influence and participation in a municipality's leisure-, cultural-, and democratic activities.

Theories: citizenship, participation, and situated learning.

The study was conducted as participatory action research with seven co-researchers and staff from a Swedish municipality. The co-researchers were seven young adults who have ID. Five staff from the municipal organization constituted a project group. The co-researchers participated in two single interviews each, three focus group interviews, and three actions. The staff from the municipality took part in a focus group interview and a survey.

The action Influence Café was organized as a meeting place on three occasions.

To support dialogues with the co-researchers, the method of Talking Mats was used during the individual interviews, while photographs on an iPad were used during the focus group interviews.

Results: young adults who have ID experienced exclusion in leisure, culture, and democratic activities and had difficulties gaining influence as citizens.

The results indicate that a shift needs to take place, away from the lack of knowledge and abilities of young adults who have ID, towards the knowledge deficits and normative beliefs of those around them.

A conclusion that can be drawn from the study is that empowerment and the ability to influence society can be created if young adults who have ID are made visible and begin to be seen as a resource, and thereby they can be allowed to take their place as citizens.

The right to research: constructing capacity and informed consent for people with an intellectual disability during ethical approval

Amy Russell,

University of Leeds, Leeds, United Kingdom

Health research creates the evidence base for the delivery of healthcare. Yet inequalities in health research inclusivity upstream create an evidence base that does not represent people with disabilities and can exacerbate the inequalities in access to, and outcomes, of healthcare.

Research that recruits participants from the NHS in the UK requires ethical approval from the Health Research Authority. The HRA is open about its commitment to inclusion, in its committees and research participants. However, ethics committees are made up of volunteers who give their time to provide a service to support the regulation of research. Research applications must take a certain format and comply to certain criteria. Committee members balance a number of competing demands including a commitment to the protection of potential participants and a requirement to facilitate the research approval process.

This study will examine the exclusion and inclusion of people with an intellectual disability in health research. People with a learning disability are often excluded from research based upon the assumption they lack capacity to participate and/or are unable to provide informed consent and this is in addition to other barriers (e.g. environmental) that people with disabilities may face during health research participation.

This paper will report on the findings of 36 observations of HRA research ethics committees during 2021/22 as they discuss capacity and consent in relation to recruitment into health research. It will examine the circumstances, projects and populations who trigger discussions of capacity or consent and the way these topics are constructed. It will ask questions about who has the right to participate in research, the role of the ethics committee as gatekeepers of research and draw attention to the contested status in research regulation of people with an intellectual disability.

11-05-2023

14:25 - 15:45 - Disability and the lifecourse I - Learning Disability and Autism Research at Manchester Met Hilton Nordica meeting room H /

- Moderator: Chris Hatton, Manchester Metropolitan University

‘What’s your 10 minutes of Britney?’ Using a Capability Approach to think differently about supporting people with learning disabilities

Sara Ryan¹, Siabhainn Russell²

¹ *Manchester Metropolitan University, Manchester, United Kingdom*

² *University College London, London, United Kingdom*

Sen's Capability Approach (CA) has been influential in developing understandings of individual wellbeing to reduce social injustices yet remains an under-developed approach within social care. The key underpinning principle of CA is that everyone is worthy of respect and seen as being equal. For Sen, the substantive freedom people have to do things they value is key to wellbeing. In the Flourishing Lives project, we drew on CA to explore how people with learning disabilities can be better supported to lead flourishing lives within a UK policy, practice and sometimes research context of the continuing homogenisation of people with learning disabilities, and worsening lives due to austerity cuts and impacts of COVID-19.

The Flourishing Lives project had three stages: a literature review identified key components to a good life; interviews and focus groups with 73 people with learning disabilities or family members explored these components; and a learning community of people with learning disabilities, family carers, support workers, managers and academics thought about how three key areas emerging from our initial analysis – confidence, belonging and thinking ahead – could be translated into the everyday practices of support staff and providers. Our focus on substantive freedoms in the research processes led to the identification of '10 minutes of Britney' as one example of having the freedom to do something that directly impacts our sense of wellbeing. As the Britney fan, a support manager commented, her 10 minutes of Britney was similar to 10 minutes in the fresh air for someone she supports who loves to feel the wind on their face and yet his freedom to do this was curtailed by service structures. Here we further reflect on how the simplicity of a concept that has relevance for all our lives, could potentially shift inertia that characterises learning disability support.

The Coronavirus and people with learning disabilities project: An overview

Chris Hatton,

Manchester Metropolitan University, Manchester, United Kingdom

Both in the UK and internationally, it is clear that the COVID-19 pandemic has widened the existing health and social inequalities experienced by people with intellectual disabilities, with much higher COVID-19 infection and death rates and essential services and supports being withdrawn. A UK-wide research project has been tracking the experiences of adults with intellectual disabilities through the COVID-19 pandemic. Around 500 adults with intellectual disabilities and a further 300 family carers of adults with intellectual disabilities shared their experiences via remotely conducted structured interviews or online surveys three times, from December 2020 to August 2021. A follow-up wave of interviews and surveys has gone back to people in August-November 2022. By the summer of 2021, there were 6 key messages from the project: people were doing their bit to keep themselves and others safe; people were paying a price for this; services and support had not returned to pre-pandemic levels; for some people there were some good things emerging from the experience of the COVID-19 pandemic; the general lifting of COVID-19 public health protection measures in the UK resulted in some people's lives becoming more restricted; the

impact of the COVID-19 pandemic was continuing and was unlikely to be short-term. An overview of these and additional findings from the most recent follow-on wave will be presented, together with a brief discussion of the UK policy response.

Sticky labels and their consequences: people with learning disabilities and 'behaviours that challenge others'

Magdalena Mikulak¹, Sara Ryan¹, Arne Mueller¹, Lisa Davidson², Pam Bebbington², Dawn Wiltshire², Liz Tilley³, Susan Ledger³

¹ *Manchester Metropolitan University, Manchester, United Kingdom*

² *My Life My Choice, Oxford, United Kingdom*

³ *Open University, Milton Keynes, United Kingdom*

'Behaviours that challenge others', or 'challenging behaviours' are attributed to 20 per cent of people with learning disabilities. 'Behaviours that challenge others' is not a diagnosis, rather it something people are labelled with, often in ways that erase their agency, choice and at times, their very humanity. In this presentation, drawing on Sara Ahmed's work on affect and how words generate effects through repetition, we examine how that label is produced and contested in adult social care settings, demonstrate its stickiness as it follows people throughout their lives, and examine the consequences it has for those labelled with it.

Based on interviews with social care support staff, managers, and commissioners, we argue that how such behaviours are understood matters for the support people with learning disabilities receive and maps onto their consequent inclusion, or exclusion from the society. By pointing out the harms it carries for people who receive it, we highlight the constructed and relational nature of that label and question how useful, and for whom, it is.

Supporting Autistic Adults' Intimate Lives

Monique Huysamen, Marianthe Kourti, Chris Hatton

Manchester Metropolitan University, Manchester, United Kingdom

Intimate relationships are an important aspect of most adults' lives. However, autistic people face more social barriers to, and experience greater anxiety around, intimate relationships. This leads to increased loneliness and social isolation. National health and social care systems should recognise and work to reduce these inequalities. Supporting Autistic Adults' Intimate Lives (SAAIL) is a qualitative research project that explores autistic people's experiences with sex, relationships, and intimacy and investigates how autistic adults themselves believe health and social care can better support their intimate lives. Data was collected using a two-phase process. First, semi-structured interviews were conducted with 25 participants. Using the insights gained from these interviews, asynchronous text-based forum-style focus groups were designed. These focus groups were facilitated by an autistic researcher and were entirely autistic spaces. Five focus groups were conducted with a total of 48 participants. The preliminary findings show that autistic people faced a variety of barriers to establishing and maintaining intimate relationships, these barriers include the

indirect and ambiguous communication patterns characteristic of flirting and sexual scripts in our majority neurotypical society; feeling sexually inexperienced compared to peers; low self-esteem; social anxiety; past experiences of trauma and a lack of trust in others; and accommodating sensory needs and preferences within normative expectations for relationships and living together. Based on participants' accounts, we present some of our key recommendations for how autistic adults can be better supported by health and social care practitioners. These include providing autistic people with a "menu" of the available support options; providing support and resources on sex and relationships in a wide variety of formats to take into account the diversity of the autistic population; and supporting autistic people to embrace and articulate their needs and preferences, including those around alternative relationship configurations and living arrangements.

11-05-2023

14:25 - 15:45 - **Deafness II with International Sign Language - Culture, knowledge and language** Grand Hotel - Háteigur /

Rethinking Deafness, Film and Accessibility: exploring how Deaf people experience suspense in film

Ryan Bramley¹, Kirsty Liddiard¹, Beth Evans²

¹ *The University of sheffield, Sheffield, United Kingdom*

² *Paper, Sheffield, United Kingdom*

Suspense is key to any form of successful storytelling. In film, suspense is deployed in an often audiocentric manner: the lengthy periods of silence in *A Quiet Place* and the iconic, quickening theme in *Jaws* are both designed to create the impression that something is about to happen, with the intention of keeping audiences engaged with the narrative. However, in a medium that relies heavily on audio techniques to enact suspense, are d/Deaf audiences marginalised?

Working with *Paper*, a user research and service design company, we interviewed a small group of Deaf people to explore how the quality of accessibility features, like captioning and subtitling, impacts their experiences of suspense across a range of film genres. We acknowledged that we were a research team composed of hearing people, with no embodied experiences of Deafness and/or audism. Therefore, to effectively embed Deaf-centric approaches and Deaf people's lived knowledges at the core of the project, our Advisory Group, made up of Deaf people, actively guided the project, its themes and approaches, and provided expert knowledge across the process to ensure inclusivity for Deaf participants and their communities.

Whilst being careful not to generalise the lived and embodied experiences of a relatively small group of people across the Deaf community as a whole, our interviews revealed the importance of cinematic suspense for our participants, and their feelings of frustration when they experience poor captions (or in some cases, no captions at all) and myriad other forms of inaccessibility. In this talk, we will summarise our key findings from the *Rethinking Deafness, Film and Accessibility* project, as well as a reimagining of what a more inclusive cinematic experience might look like. We argue that co-design is needed between

filmmakers, captioners and Deaf consultants throughout the film production process to achieve this.

How can Indigenous knowledges of inclusion, belonging, and self-determination promote healing pathways for people with disability and their communities?

Scott Avery,

Western Sydney University, Liverpool, Australia

There is an increasing body of research that has exposed the intersecting and multi-faceted discrimination and structural barriers to inclusion that people with disability encounter in securing the rights to inclusion. Uni-dimensional approaches to rights and public policy frameworks that view disability and Indigenous communities as separate groups have proven inadequate in addressing the intersecting inequalities experienced by marginalized groups within the disability community, and the hard-wiring of rights and policy silos continue to frustrate those who must traverse multiple mechanisms in their pursuit of social justice.

Presented by a profoundly deaf Indigenous scholar from the First Nations disability community in Australia, this paper will illustrate how an Indigenous cultural knowledge of inclusion acts as a moderating effect upon the social wellbeing and inclusion for disabled people and communities. Embodying cultural values that respects all people for their inherent worth, and an understanding that 'belonging' is created by coming together as a community, Indigenous knowledges of disability and inclusion are a catalyst for healing pathways for people with disability who have experienced acute social marginalization. In coming together, these communities can foster community-wide healing through collective expressions and acts of self-determination.

Framing experiences of discrimination, trauma, then healing as a pathway situates cultural inclusion as the nexus where the personal rights of inclusion can converge with the self-determining rights of communities. The voice and experiential knowledge of the Indigenous disability community has been central in the conceptualisation of a healing pathway and its translation into disability policy frameworks. This presentation will conclude by inviting a reflection on what healing might look like if an Indigenous philosophy of disability and inclusion could be extended to *all* people with disability and their communities.

On whose terms? - Deaf migrants' experiences of integration in Sweden

Duggan, Holmström

Stockholm University, Stockholm, Sweden

This presentation critically explores the paradoxes of Sweden's requirements for 'full integration' into Swedish society and deaf migrants' language learning journey. Data is drawn from an ongoing research project called *The multilingual situation of deaf refugees in Sweden* which investigates deaf migrants' language situation in four folk high schools (equivalent to adult education centres) across Sweden. The data consists of background interviews with 43 deaf migrants as well as in-depth interviews with 14 teachers. The interview data reveal complexities in the deaf migrants' language learning journey and the current obstacles in society that not all of the migrants may be able to tackle.

Using a crip theory perspective, the presentation will examine the expectations of society, particularly governmental agencies, on deaf migrants' integration into society and whether

'full integration' is possible for this particular group. Currently, an analysis of a selection of interview data shows that the responsibility lies heavily on deaf migrants to be able to actively participate in Swedish society. This is mainly through learning Swedish Sign Language (henceforth STS) *and* written Swedish. Allocation of funding and time for deaf migrants to learn two new languages simultaneously are based on the agencies' standardised guidelines for the time and pace for hearing migrants to learn only *one* language. The data also shows that there is a need to examine structural inequalities that impose obstacles for deaf migrants from integrating into society. For example, communication with public services requires the ability to use STS with interpreters, the ability to read and write (e.g. personal information, letters, and emails), the ability to comprehend questions asked and to accurately answer what is being asked (e.g. interviews with Migrationsverket). These expectations may be unattainable for deaf migrants and thus led to an unlikely possibility to achieve "full integration".

Shared (Digital) Picture Book Reading with DHH Children in Spoken and Sign Language – First Results of a Pilot Study with Parents and Pedagogical Professionals

Anne Stutzer¹, Claudia Becker², Christian Müller¹, Mabu Aghaei², Nora Eisinger¹, Swantje Marks², Laura Avemarie¹

¹ *Ludwig-Maximilians-Universität, München, Germany*

² *Humboldt-Universität, Berlin, Germany*

Background: Data proves that 40 % to 50 % of deaf and hard-of-hearing (DHH) children have difficulties in written and spoken language. Shared book reading is one approach to language support that has been shown to be effective in numerous studies with typical hearing children. Although shared book reading is known to be a central developmental stimulus, 40 % of German families rarely or never read to their children. In families with DHH children, parents read picture books less and at more moderate levels because of increased communicative barriers. Additionally, few professionals can read to DHH children in sign language due to a lack of sign language skills. Reading digital picture books is potentially a way of increasing book reading in families, with one-fifth of families using digital picture books – even in families that do not use printed picture books.

Purpose: The research project *Reading Digital: Inclusive Language Education with Multilingual Digital Picture Books in Spoken and Sign Languages* (ReaDi), funded by the German Federal Ministry of Education and Research (October 2022 to September 2025) has already gathered first empirical data on the characteristics of shared (digital) picture book reading with young DHH children using sign and/or spoken language in Germany. The study will also focus on identifying the hurdles parents and pedagogical professionals face in shared (digital) picture book reading with DHH children and the support measures they would like to receive.

Method: Within a participative approach, questionnaires will be used in a pilot-study to survey 75 parents and 15 pedagogical professionals of DHH children of kindergarten and school age.

Results: First insights from the pilot study in January 2023 will be presented before the main data collection starts in summer 2023.

11-05-2023

14:25 - 15:45 - **Services I - Personal assistance** Grand Hotel - Huginn

What's gone wrong with self-directed support? Why has policy not secured transformative change for disabled people in Scotland?

Charlotte Pearson, Nick Watson

University of Glasgow, Glasgow, United Kingdom

It is now ten years since Scotland enacted the Self-Directed Support Act, a policy that aimed to improve choice and control for those who use social support and promote co-production between users and providers. Yet a policy that pledged to transform social care has failed to do so, leaving the framework for provision unchanged with the bulk of social care still being provided directly by local authorities. The lack of transformative change has been broadly seen as a problem of implementation, rather than one of poor design. To resolve these problems the Scottish Government recently commissioned an independent review of adult social care, the Feeley review. Two of its core recommendations to challenge the status quo in social care were the establishment of a National Care Service (NCS) and the incorporation of human rights. In this paper we draw on a series of interviews and focus groups with disabled people's organisations, the third sector, social workers and other public sector workers, to explore what has gone wrong and what comes next. In our analysis we explore five key themes. First, the problems around implementation and why local authorities still remain the key providers of care. Second, we look at resource and the effect of what has become a crisis-led support service and its role in the marginalisation of direct payments. Third, we unpack the disconnect between the 3 main interest groups and how this has led to each of them pulling in different directions and failing to establish a common voice for SDS. Fourth, we examine rights and rights-based care to explore what a human rights-based approach would look like and in the final section we examine a policy reform agenda which promotes increased centralisation of services through the establishment of a new national care service.

How can the shift towards a medicalised application of state-funded personal assistance in Sweden be understood?

Helene Von Granitz, Karin Sonnander, Ulrika Winblad

Uppsala university, Uppsala, Sweden

Personal assistance (PA) in Sweden, regulated by the Act concerning Support and Service for Persons With Certain Functional Impairments (LSS), aims to provide good living conditions for persons with severe functional disabilities. However, studies show increased support for medical and nursing care, i.e. a medicalisation of PA, instead of providing support to promote the PA user to live like others, namely working or studying. This study aims to understand how the medicalisation of PA has developed. Thematic analysis of 15 interviews was conducted with public officials at the Swedish Social Insurance Agency, responsible for developing and managing the PA-allowance granting-process. The results reveal a medicalisation of the PA-allowance granting process that has been made possible due to external and internal factors. External factors include case law, legal changes in the

LSS Act, marketisation of PA services, changed policy priorities, weakened PA collaboration structures and inadequate monitoring of PA outcomes. Internal factors found were an extensive complexity of the PA-allowance granting process and strained organisational pressure on the SSIA officials. In particular, this study illustrates that the SSIA regime logic has thoroughly influenced the LSS policy outcome with time. The regression of PA, by gradually resigning to a medicalised application, demonstrates weakened conditions for Swedish disability policy through the LSS Act to fulfil Article 19 of the UNCRPD. The result emphasises the need for social reform applications to be calibrated towards the original policy goals to uphold policy compliance, and to maintain continuous understanding and discussion of the policy outcome over time.

After deinstitutionalisation – trends in living arrangements and employment for intellectually disabled people in Norway

Jan Tøssebro, Christian Wendelborg

NTNU Social Research, Trondheim, Norway

Background. Norway closed all institutions for intellectually disabled people in a swift move from 1991-1995. The reform was guided by slogans like normalisation and participation, and it was an expressed goal that intellectually disabled people should have access to living conditions that are acceptable compared to other people.

Aim. The litmus test of such a reform is not what happens during intensive and politically attended reform years, but what the long-term developments are. The aim of this paper is to present long term (nearly thirty years) development in two core areas – living arrangements (housing) and employment.

Methods. The presentation is based on a) survey data on the living conditions of intellectually disabled people at four points in time: 1994, 2001, 2010 and 2021 (respondents: prime care workers), and b) national register data on employment (2014) and housing conditions (2020) of people registered as intellectually disabled in the social security system.

Results. Data on housing conditions shows that a low and stable proportion live in apartments independent of group homes, that an increasing share of the group homes have communal rooms, and that the number of residents per group home has increased substantially – from 3.8 in 1994 to 9.1 in 2021. A minority have ownership to their apartment, and those not owning their apartment have limited choice regarding where they live and with whom. The housing economy is substantially deteriorated as rents has doubled (fixed prices) and that housing allowances are phased out. Participation in the labour market continues to be low, and intellectually disabled people have disappeared from labour market measures established for this group in the 1990s.

Discussion. Possible explanations of these worrying trends are discussed and also to what extent it could be called reinstitutionalisation.

Formal help for persons with Multiple Sclerosis - What background factors are associated with usage of personal assistance and home help in Sweden?

Daniel Ståhl¹, Emilie Friberg²

¹ *University of Gothenburg, Gothenburg, Sweden*

² *Karolinska Institute, Stockholm, Sweden*

Background: Multiple sclerosis (MS) is a chronic neurological disease that mainly affects persons from young adulthood. MS may cause several different symptoms, some which entails a need for help in daily life.

Aim: The aim of this study was to explore the association between background factors and use of personal assistance and home help services (home help) among persons with MS in Sweden.

Methods: The study is based on cross-sectional survey data merged with register data and included 3863 persons with MS between the ages 20-51. Binary logistic regression analyses were performed to identify factors associated with use of personal assistance and home help.

Results: The central finding of this study was that grade of impairment was the most important variable associated with use of both personal assistance and home help. To live by oneself and receiving sickness benefit were also both associated with use of personal assistance and home help. Stating a visible symptom of MS as the most limiting one and having a disposable income below the limit of risk of poverty was associated with use of personal assistance. Receiving informal help, meaning unpaid help, was associated with use of home help. Several background factors were controlled for but were not related to differences in usage of formal help. The results indicate no significant differences that could be attributed to unequal distribution by demographic characteristics such as gender, birth country or type of living area. However, differences were found between those using personal assistance and home help. The latter were mainly affected by an invisible symptom, suggesting a plausible difference in the possibility of obtaining the more comprehensive help form of personal assistance. Users of home help also used informal help to a greater extent than users of personal assistance, which may indicate that home help were insufficient.

11-05-2023

14:25 - 15:45 - **Human rights I - Disability, courts and justice** Grand Hotel - Hvammur /

- Moderator: Eliona Gjeczaj, University of Iceland

The court experiences of defendants with cognitive impairments in England

Edmore Masendeke,

University of Leeds, Leeds, United Kingdom

This presentation focuses on the support needs of defendants with cognitive impairments in relation to their ability to give evidence and understand what is happening in court. Concerns have been raised regarding the effectiveness of the support measures which have been put in place for such defendants in England. However, there is a general lack of empirical

research into the effectiveness of these support measures, and little is known about the views and experiences of defendants with cognitive impairments. Therefore, this research was carried out to find out more about the courtroom experiences of defendants with cognitive impairments and the effectiveness of existing support measures. Nine former defendants with mental health conditions, learning disabilities, autism or dyspraxia were interviewed for this research. This presentation will discuss the extent to which the existing support measures address support needs of defendants with cognitive impairments and the shortcomings which were highlighted by the participants.

What does justice look like for parents with intellectual disabilities in custody deprivation cases?

Hanna Björg Sigurjónsdóttir, James G. Rice

University of Iceland, Reykjavik, Iceland

Article 13 of the UN Convention of the Rights of Persons with Disabilities frames access to justice as primarily a matter concerning legal proceedings within the justice system. As critically important as this is, within the context of custody deprivation pertaining to parents with intellectual disabilities access to justice looks rather different. Drawing upon a range of studies conducted in Iceland, the evidence shows clearly that once a child protection case involving parents with intellectual disabilities has become a matter for the courts the outcome almost always favors the child protection system. As will be discussed, in the rare instances in which a parent ultimately prevails over an unjust deprivation order, this is only accomplished after an extensive fight through the Icelandic court system at multiple levels, and long after which a great deal of harm to the family has been caused. As we will argue, in the context of these cases access to justice is better accomplished through preventing a case from coming before the courts, as justice is rarely experienced by these parents going through the courts due to a number of entrenched and systematic failures.

Disabled Women and Access to Justice: accommodations in Icelandic Courts

Eliona Gjeca,

University of Iceland, Reykjavik, Iceland

Most research on violence against disabled women has focused on the forms and frequencies of violence, how violence affects disabled women's mental and physical health, and access to support services. However, limited research has focused on access to justice for disabled women who have been subjected to violence. There is little knowledge and understanding about the reporting and prosecution of violence against disabled women internationally and in Iceland, where the research presented here was conducted. Using an interdisciplinary approach, the research aims to contribute to a new and holistic understanding of the lived experience of disabled women as well as those supporting them thorough detection, reporting and prosecuting violence. Drawing on data collected through qualitative interviews with disabled women, lawyers, police, prosecutors, judges, Rights Protection officers and other support persons, in conjunction with document analysis, the presentation will discuss procedural and reasonable accommodations in Icelandic courts from the survivor/victim's perspective. It will also highlight the gaps in the justice system,

individual approach of justice workers to provide accommodations, and the lack of disability-rights-based training for all within the justice system.

Rights protection for parents with intellectual disabilities

Sara Stefánsdóttir,

University of Iceland, Reykjavík, Iceland

Forced sterilization is no longer a common method used in Iceland to prevent people with intellectual disability (ID) from becoming parents. Currently, one of the key barriers that prevent people with ID from parenting is the result of lack of proper support in the parenting role and problematic child protection (CP) interventions which often lead to child removal. Studies have shown that parents with ID, among other marginalized groups, are oppressed in the process through not having their voice heard or the means to fight or dispute decisions made that involve their family life. Since 2011, parents with ID living in Iceland can be supported by a special office of Rights protection for disabled people funded by the Icelandic government. The purpose of this qualitative study was to research and analyse how rights protection officers go about in their work supporting and safeguarding the rights of parents with intellectual disabilities. Data were obtained through in-depth, semi-structured interviews with rights protection officers (RPO) working in different parts of Iceland. Reflexive thematic analysis was used to analyse the data. The results shed light on some of the barriers the RPOs face in their work in safeguarding the rights of parents with ID who are involved with CP and the judicial system. This contribution also describes some of the methods RPOs use in their efforts to bring about a more just procedure leading to better outcomes for the parents, concluding with suggestions for improved rights protection for parents with ID.

11-05-2023

14:25 - 15:45 - Work and employment I - Crafting creative connections. Constructing collaborative interdisciplinary space for the advancement of disabled people and work Hilton Nordica meeting room I /

- Moderator: Jannine Williams, QUT

The materialisation of gender and disability in the workplace: expanding the social relational model of identity

Gemma Bend,

University of Huddersfield, Huddersfield, United Kingdom

Disabled people and women continue to be marginalised as 'inferior' subjects compared to their able-bodied and male counter parts (Fielden et al., 2020). This paper focuses on how organisations include or exclude disabled workers through their discursive and material arrangements. A social relational model of identity notes the interaction between impairment effects/sex (the private lived experience of an impairment or sex) and a disability/gender (the public experiences of social oppression) (Thomas, 1999). This paper, however, seeks to expand the social relational model of disability with a sociomaterial affective model of disability, which accounts for the relational intra-action between the social/discursive and the material world. Drawing upon a feminist-posthumanist-performativity lens I critically explore how and in what way material phenomenon and discursive practices are entangled to affect knowing and being (Braidotti, 2019; Fox and Aldred, 2017). Particularly I argue that disability and gender are performatively enacted during sociomaterial entanglements in (non)workspaces (Bend and Priola, 2021). This paper will explore how and why organisational spaces and practices, often formed around able-bodied and gendered norms, lead to the materialisation of a disabled and gendered body in a UK employment context.

The findings add empirical evidence across multiple types of employment contexts, on how material phenomenon and discursive practices mutually affect one another, which through their interaction materialise their bodies as being disabled and gendered. The qualitative paper draws upon data from 24 semi-structured interviews with disabled women and men. The paper will discuss the main theme materialisations of identity with 3 subthemes: Employment difficulties, Organisational environment, and Organisational leadership practices. The findings demonstrate that organisations need to critically reflect on how material-discursive practices create and constrain inclusive workplaces for disabled women and men. Theoretically the paper adds empirical evidence to expand the social relational model of disability to a sociomaterial model.

Negotiating a job – flexible job design in Denmark

Thomas Bredgaard,

Aalborg University, Aalborg, Denmark

Mainstream labour market research presume that jobs are given and predefined implying that individuals must adapt to jobs. However, to make the labour market more inclusive, jobs also need to adapt to individuals with disabilities.

This basic idea was acknowledged in the early job design literature and later in the job crafting literature. In the disability literature, ideas about job design are alluded to in the literature on supported employment, customized employment and individual placement and training.

The Danish flexjob program is a clear example of job design. The flexjob program is an employment program that integrates persons with permanently reduced work ability in the labour market by adapting their work hours, job functions, work intensity and wages.

In this presentation, I will revisit the job design literature to explore the lessons and potentials for people with disabilities and examine the flexjob program as a specific case of job design. The presentation builds on the first finding from interviews with persons in flexjobs, employees in jobcenters and employers, as well as a representative national survey on employers' attitudes and experiences with flexible jobs.

Consequences of social missteps in an ableist context: the need for A care-based DIVERSITY APPROACH

Sophie Hennekam ,

Rennes School of Business, Rennes, France

Adopting a collaborative autoethnographic case study approach, this article explores the lived experience of a healthcare professional who was accused of inappropriate sexual behavior and who was later diagnosed with Autism Spectrum Disorder (ASD) rather than a paraphilic disorder. Drawing on multiple interviews and diary entries of the research participant during a period of 21 months, we report on the individual's journey, during which he reflected and theorized in real time with the researchers. We observe how his neurodiversity influenced his practice and career and highlight the ongoing deleterious consequences of making social missteps for this neurodiverse individual. A care-based diversity approach is positioned as a viable alternative to managing inappropriate social behavior to allow for a more holistic, attentive, and contextually sensitive perspective on diversity and to embrace the subjective nature of reality.

The intersectional identity work of entrepreneurs with disabilities: focusing on disability, gender, and entrepreneurship

Anna Hidegh¹, Carmen Svastics ², Sára Csillag ³, Zsuzsanna Győri³

¹ *Corvinus University of Budapest, Budapest, Hungary*

² *Eötvös Loránd University, Budapest, Hungary*

³ *Budapest Business School, Budapest, Hungary*

Studies embedded in an intersectionality approach investigate the co-existence, interplay and mutual reproduction of different identity positions (Collins, 2020; Crenshaw, 1991; Hancock, 2007). There is a growing interest in the intersection of privileged and marginalized identity positions (Booyesen, 2018; Weldon, 2008), such as the intersection of entrepreneurship with whiteness and gender (Heizmann & Liu, 2020), or with ethnicity (Adeeko & Treanor, 2022; Barrett & Vershinina, 2017). However, the literature on entrepreneurship is dominated by a discourse on the intersection of gender and entrepreneurial identity (Heizmann & Liu, 2020), while extending the focus on social categories like disability, race, class and sexuality is long overdue (Williams & Patterson, 2019). Taking a constructionist perspective (Hancock, 2016), and adopting an

intracategorical approach (McCall, 2005) we explore ‘the intersection of gender and disability within entrepreneurship research’ (Williams & Patterson, 2019, p. 1706). Jammaers and Zaroni (2020) also claim that an intersectionality approach might enrich our understanding of the identity work of entrepreneurs with disability (EWD) while others call attention to the broader sociological relationships between inequality and entrepreneurship (Martinez Dy, 2020). People with disabilities (PWD) are largely ‘invisible’ (Procknow & Rocco, 2016), a ‘forgotten minority’ (Cooney, 2008) in entrepreneurship studies (Parker Harris et al., 2013, 2014; Saxena & Pandya, 2018; Williams & Patterson, 2019), even though they are more likely than non-disabled people to be entrepreneurs or self-employed (Cooney, 2008). EWD are a huge and heterogeneous group (Renko et al., 2015), whose diverse experiences, intersections with other minority categories need to be explored. In this empirical paper, we would like to examine how EWD navigate their identities in the crossroads of entrepreneurship, disability, and gender, shedding new light on the interplay of potentially privileged identity positions such as being an entrepreneur and/or a man, and marginalized categories such as being disabled and/or a woman.

The hybrid work experience of disabled people: lessons from the pandemic

Eline Jammaers¹, Noortje Van Amsterdam², Ive D Klinksiek³

¹ *UHasselt, Hasselt, Belgium*

² *Utrecht University, Utrecht, Netherlands*

³ *UCLouvain, Louvain, Belgium*

The mass transfer to homeworking during the Covid19 pandemic may have been a pivotal moment in “levelling the playing field” for people with a disability, chronic illness or neurodivergence who were not or little allowed to telework before and could suddenly benefit from reduced travel efforts and increased self-care possibilities during work hours. The pandemic has certainly increased employer acceptance of these arrangements, regardless of (dis)ability. Moreover, there has been an increasing attention to issues of mental and physical health in the workplace over the past two years in both the media and business practice, accelerated by the health crisis, which may also have a positive spillover effect on disability-inclusion. For this study, we conducted 50 interviews with disabled workers who remained employed in a hybrid or temporarily exclusive homeworking regime during the pandemic. The research objective was to find out whether the pandemic brought upsides for disabled workers who remained employed? Two research questions guided the thematic data analysis: (1) What were the benefits and downsides of teleworking during the pandemic for the respondents; (2) To what extent did they feel the Covid-19 pandemic led to more corporate caring cultures at work?

11-05-2023

14:25 - 15:45 - **Inclusion I - Inclusion in diverse contexts** Grand Hotel - Ásgarður

Developing Potential Through Articles 27 and 30 of the UNCRPD

Callus,

University of Malta , Msida , Malta

This paper is based on the outcome of an inclusive research project carried out in Malta, through which the research team worked with persons with intellectual disability to create video CVs highlighting their skills and achievements. Seventeen video CVs were created in total. This paper will discuss the content of the videos, focusing on what the 17 persons with intellectual disability achieved with particular reference to the world of work and to artistic and sporting activities, with reference to the rights established in these areas in Articles 27 (Work and Employment) and 30 (Participation in cultural life, recreation, leisure and sport) of the UNCRPD. Many of the 17 project participants are already in employment, on a part-time and full-time basis, and work in a variety of settings. Others are looking for work. Their experiences in this area related to Article 17. Apart from this, many participants also engage in activities related to Article 30, including sport, drama, dance, music and painting. The factors that enabled these achievements will be discussed, including support from families, employers and colleagues and disability organisations, as well as the persons' self-determination. The discussion will also include an analysis of feedback received about the videos during a seminar. The positive impact that these achievements can have on the individuals concerned and on society as a whole will be discussed. The paper will also consider the issues raised by a sole focus on the abilities and the risk it may raise in playing into ableism.

(The conference presentation will be done by the project team leader. The project team intends to submit the article related to this presentation to the SJDR special issue on *Disability Human Rights*.)

Building inclusive cultural spaces together

Susana Rojas-Pernia¹, Ignacio Haya-Salmón², Josep M^a Sanahuja-Gavaldà³, Antonio Pérez-Romero³

¹ *Universidad de Cantabria, Santander (Cantabria), Spain*

² *Universidad de Cantabria, Santander, Spain*

³ *Universitat Autònoma de Barcelona, Barcelona, Spain*

This work is part of the Erasmus+ project "Fostering social inclusion for all through artistic education: Developing support for students with disabilities - INARTdis". The project involves cultural and socio-educational institutions from Austria, Germany, North Macedonia, Portugal and Spain.

In the three-year project, different actions are developed with the aim of promoting inclusion through the arts, fostering collaboration between educational and cultural institutions and recognising, among others, the agency of people with intellectual disabilities in the transformation and improvement of artistic and cultural spaces.

This paper focuses on one of the first phases of the project in which the inclusivity of cultural centres was assessed and strengths and opportunities for improvement were identified. Overall, 22 cultural and educational institutions from different stages (primary, secondary and post-compulsory) participated.

Specifically, we collect here the contributions made by visitors, co-researchers and artists with intellectual disabilities in two Spanish regions. For this purpose, different research techniques were used to promote the participation of visitors and co-researchers. Through the taking of photographs, participant observation, and discussion around ideas-force during and after the visits, aspects of cultural institutions that facilitate or limit access and participation in these spaces for any person were analysed.

As pointed out by the participants, among other issues, it is important for anyone to have access to new learning spaces different from more usual contexts. Moreover, it is essential that museums or cultural centres develop actions or activities in which anyone can get involved. Their reflections were collected, among other productions, in the *Guide to building inclusive cultural spaces*.

An 'Academic Workplace' on De-Institutionalization. Partnering practice, policy, and academia to redefine De-Institutionalization and inclusion from a socio-spatial and cross-policy approach.

Toon Benoot, Dries Cautreels, Matthias Remmery, Griet Roets, Rudi Roose

Ghent University, Gent, Belgium

De-institutionalization (DI) is framed and recognized internationally as a lever for the realization of inclusion for citizens with disabilities. There is a continuing need to pursue inclusive living, housing, and working through an expansion and differentiation of ambulatory care and support in the community. That is above all the case in Flanders (the Dutch-speaking region of Belgium) which has a very slow response to DI compared to the Nordic countries. The urgency of the issue is widely supported, while there is no consensus as to how to address it since DI refers not only to the location and nature of the architectural and spatial embedding of the living environment, but also to an institutional culture.

To support innovation in policy and practice and to gather knowledge on conceptions and strategies of DI, the Flemish Agency for People with Disabilities provided funds to establish the *academic workplace de-institutionalization* (AWDI). In the coming years, the AWDI is committed to connecting the experiential knowledge of people with disabilities, their networks, professionals, policymakers but also architects and urban planners to stimulate innovation in the field and in policy and create qualitative living environments.

The presentation will reflect how this collaboration between policy, practice and research took shape, what socio-spatial research projects have taken root in this collaboration, and the various research methods used. I will outline how in Flanders, through collaboration between different domains, attempts are being made to contribute to the development of knowledge on transforming residential settings into inclusive living environments.

"Disability is not a word that we use": Supporting disabled young people leaving care in Norway.

Ingri-Hanne Brænne Bennwik², Berni Kelly¹, Inger Oterholm²

¹ *Queen's University Belfast, Belfast,, United Kingdom*

² *VID Specialised University, Oslo, Norway*

This paper presents findings from a study of support for disabled young people leaving care in Norway. The study involved qualitative interviews with eight disabled young people, aged 19-27, who had left care at least six months previously. Fourteen social workers providing aftercare support in child welfare services were also interviewed.

The paper focuses on how support for disabled care leavers in Norway is adversely affected by a limited understanding of disability within child welfare services and a medical model approach whereby those who meet the threshold for adult services are excluded from aftercare support whilst others remain in child welfare services but are subjected to unrealistic, normative assumptions. Although young people described bodily experiences of impairment, diagnoses or pain/fatigue and recounted experiences of oppression, they were reluctant to use the term disability. They were acutely aware, however, of how they were categorised by service providers as either aftercare youth progressing towards normative adult goals or disabled adults who should access specialist adult services. Their intersecting needs were not fully met in either category as child welfare services ignored disability-related experiences and adult services focused on impairment, overlooking their aftercare needs. Despite policy intent, there was very limited coordination across child to adult services leaving youth isolated and unsupported as they navigated their transition from care. Young people, therefore, had to self-advocate to have their needs met.

These findings highlight the need for a more critical understanding of disability within child welfare services that disrupts binary approaches to service provision and facilitates person-centred support to meet multiple, intersecting needs. Social justice and anti-oppressive practice are cornerstones of effective social work practice. These findings suggest a need to strengthen this aspect of child welfare services to challenge normative and exclusionary service systems and counter the oppression experienced by disabled care leavers.

11-05-2023

14:25 - 15:45 - **Disability and the Covid-19 pandemic I** ÖBÍ 1 Sigtún
42 /

Communications on COVID19, and the experiences of people with learning disabilities and autistic people

Alison Wilde¹, Robyn Steward²,

¹ *Leeds Trinity University, Horsforth, Leeds, United Kingdom*

² *Independent, Leeds, United Kingdom*

This paper draws on a study which used inclusive methods to seek how people with learning disabilities and/or autistic people gained access to information on COVID 19 from 2020-2022. As high-risk groups, with a range of new communication needs, the pandemic

generated greater uncertainty, anxiety, panic, and risks to self and others. Optimising their well-being, and the imperatives of pandemic communications and preparedness - i.e., inclusive forms of communication which build trust and 'dispel rumors' (Vaughn and Tinker, 2009, 324), created an urgent need to understand how people with learning disabilities and/or autism are likely to access information and interpret the communications and conditions of rapidly changing pandemic rules, in the face of a vast array of information from all media, and alongside diminished forms of support.

Thirty-four interviews were undertaken with autistic people and people with learning disabilities, in the UK, focusing on their understandings of media, health-related communications and network information (e.g. from family / carers / friends/ social care agencies). These informed a survey completed in November 2022. Drawing on in-depth discussions with participants, and analysis of survey data I will outline common themes emerging in key areas. These include views on the delivery of official rules and the exclusionary design of political communications, and the varying experiences of the participants; these were often highly dependent on access to support from family and/or support organisations in circumstances where such services were much diminished. I will also demonstrate how the creativity and resourcefulness of the disabled/autistic people helped to provide much needed new resources, e.g., extending services to co-productive easy read information on COVID-19.

I will also show how the 'return to normality' is often not the case for many with many feeling ambivalent, even anxious, about the lifting of restrictions and the relative absence of new information.

Using Bliss symbolics to advance emergency information – results from a co-creation workshop with experts

Elin Vinblad¹, AnnaLisa Osvalder²

¹ *Furuboda School for People with Disabilities, Yngsjö, Sweden*

² *Chalmers University of Technology, Gothenburg, Sweden*

During the Covid-19 pandemic, it became clear that emergency management on a societal level largely failed to reach many groups within the disability community, particularly those with difficulties accessing, understanding, or responding to information.

Bliss symbolics is a symbol-based language used by persons who require the use of alternative and augmentative communication (AAC) due to severe speaking difficulties, most commonly in combination with physical disabilities. Bliss communicators often use a combination of both low-tech printed paper charts and high-tech computers with speech generating devices. While the high-tech communication programs offer the possibility to independently change and personalize the user's vocabulary, it is often a complex task with which many require help. When something unforeseen happens, a new vocabulary is needed instantly – but many emergency -specific words are not yet developed for Bliss symbolics.

The purpose of this study was to investigate what individual needs Bliss users can identify in an emergency, and to explore how these relate to national emergency recommendations. The method used was a co-creation workshop where eight Bliss expert users participated.

Using scenarios of different emergency situations, the group identified main challenges in relation to various crisis set-ups, both regarding recommended actions and how these recommendations were communicated. They also identified flaws in examples from previous emergency information given, and proposed ideas for improvements on how to interpret emergency information using the Bliss symbolics.

To conclude, Bliss users constitute a unique group of expert users, combining the need for technological, communicative, and physical adaptations. Using co-creation together with Bliss users proved to be a creative way to reach new knowledge about emergency information design. The insights also provided valuable input and an increased interest to develop this research area.

Is disability representation (in)Visible in official crisis preparation?

Linda Stjernholm,

Lund University, Tågarp, Sweden

Background:

People with disabilities are often disproportionately affected by disasters. These groups are rarely involved in crisis planning or crisis preparation. The Covid-19 pandemic has shown the negative impacts of isolation and inequality for people with disabilities and highlighted the need for additional studies in this field. Therefore, it is important to investigate how local and national stakeholders involve people with disabilities in planning for the next crisis.

Method:

Semi-structured interviews were conducted with representatives from disability organizations of people with hearing, seeing, and intellectual and physical disabilities. In addition, local and regional crisis coordinators were interviewed, and this was further explored with an analysis of official documents on crisis and disaster risk management.

Results:

Preliminary findings suggest a few points of interest: the importance of accessible information, technology, and digital inclusion as a crucial gateway to that information, and finally, the stakeholders' different viewpoints on how to move forward. The study identified gaps in disability-inclusive disaster risk reduction and the potential for closer cooperation between disability organizations and crisis planners.

Conclusions:

Factors relating to information and barriers to accessible crisis information emerged in the interviews. Future work will explore how these can be mitigated by collaboration between the different stakeholders in crisis management. Further insights into how this co-production of knowledge can be approached will be presented.

Reasonable Adjustment, COVID-19, and Crises in Disability Justice

Liam Livesley,

University of Southampton, Southampton, United Kingdom

“Reasonable adjustmentism” can be seen as one of the great successes of the contemporary disability rights movement. This is the idea that – as a matter of justice – institutions are required to make changes to their facilities and practices in order to accommodate disabled people, as long as the costs involved are not unreasonable. This is underpinned by the social model of disability, both ontologically and normatively, and is often held up as the foremost vehicle for disability justice in societies that endorse the idea.

During the COVID-19 pandemic, many disabled and vulnerablised people continued (and still continue) to protectively isolate themselves after official advice to do so had ended. This has frequently been in response to the unwillingness of other members of society to continue to practise protective measures – like masking – after these practices ceased to be mandated.

This paper asks why continued mandating of protective measures is not thought to fall under institutions’ duty to reasonably accommodate disabled people. Practices like masking are of low cost to the individuals carrying them out compared to the benefits they have for isolated disabled people. Why, then, would it not be “reasonable” to continue to mandate them?

I argue that in times of crisis – like the COVID-19 pandemic – our standard for reasonableness of adjustments shifts, becoming problematically high. That is, the costs we are willing to pay to accommodate disabled people are lower in times of crisis. I argue that this instability in “reasonableness” means reasonable adjustmentism ought not to be the sum of our ambitions for disability justice. What is seen as a reasonable cost to pay for adjustments is all too often informed by objectionable judgments about the quality of lives led by disabled people and about the value of those disabled lives themselves.

11-05-2023

14:25 - 15:45 - **Participation and inclusion - Children and youth**

Hilton Nordica - Meeting Room G /

- Moderator: Barbara Gibson, University of Toronto

Re-Orienting Rehabilitation to Critical Disability Studies: A call for Radical Reform

Barbara E. Gibson,

University of Toronto, Toronto, Canada

In this presentation I will discuss how the nascent field of critical rehabilitation studies is mobilizing to radically reorient rehabilitation practices and ideologies to align with critical disability studies. Rehabilitation and its affiliated professional disciplines continue to reproduce ableism and disablism in service, research, and education. Appeals to engage

with disability studies have been largely ignored for decades despite the profound power of rehabilitation to affect the lives of disabled people. As an enterprise historically and ideologically aligned with biomedicine, rehabilitation is largely focused on the ableist pursuit of normal: normal function, normal bodies, normal development, normal life roles. Interlinked with racism, heteronormativity, and coloniality, ableist notions of normality are deeply ingrained within healthcare. In the talk, I will begin with the premise that rehabilitation can and does provide potentially valuable services for disabled people. I explore how to capitalize on this potential while addressing the significant and ongoing harms perpetuated by current practices. To do so, I will 1) interrogate rehabilitation's core assumptions and their alignment with neoliberal ableist principles, 2) provide an overview of the emerging field of critical rehabilitation studies and its efforts to identify and address its ableist ideologies and practices, and 3) explore an example of the disabling effects of rehabilitation's promotion of independence and normalization and how 'things could be otherwise'. Rather than suggesting rehabilitation needs to be 'informed' by disability studies, I conclude with directions for radical reforms that re-orient rehabilitation to a disability studies agenda that works in solidarity with, not 'for', disabled people. I conclude with an introduction to the session aims and the included presentations.

De-territorializing rehabilitation: Experimenting with posthuman disability studies

Donya Mosleh,

University of Toronto, Toronto, Canada

Critical disability studies and rehabilitation sciences arguably occupy opposite ends of a continuum, ranging from a critical stance toward the production of disability, to a medically-derived perspective of disability as a problem requiring intervention. In attempt to bridge this divide, scholars within the emerging field of critical rehabilitation have begun to employ more 'critical' and theoretically informed orientations towards the principles and assumptions which underpin practice, policy, and research. Drawing on an array of social theories, this work questions rehabilitation's naturalized assumption that disability is abnormal and requires intervention to improve and enhance disabled people's lives. In this presentation, I add to this emerging field by experimenting with a life-affirming posthuman disability studies rehabilitation. To do this I employ posthuman epistemologies to critically interrogate how rehabilitation practices, policies, and interventions produce, or enact a particular kind of humanity which sustains distinct categories of difference such as 'disabled' and 'non-disabled'. I begin by first highlighting the prevailing humanist assumptions which predicate rehabilitation's core principles. Next, I outline my posthuman disability studies orientation and the Deleuzian concepts I employ. Finally, I draw on these concepts to consider how the particular subject position of 'the child with Duchenne muscular Dystrophy'(DMD) is a shifting assemblage, produced differentially within the context of a rehab clinic. DMD is a unique genetic disorder characterized by a weakening of skeletal muscles, which leads to a loss of physical abilities and eventual respiratory failure. My aim in engaging in this theoretical and interdisciplinary experimentation is not to advance a distinct or singular trajectory for rehabilitation, but rather, to 'de-territorialize rehabilitation'. That is, to articulate temporary lines of flight for a life-affirming posthuman disability studies rehabilitation. Such an approach offers an alternative orientation to life that extends beyond traditional humanist understandings, and recognizes differences as potentials, rather than deficits.

Disabled by ‘normal development’? Challenging ablism and developmentalism in rehabilitation for young people with ‘developmental disabilities’

Yani Hamdani,

University of Toronto, Toronto, Canada

Normal development is a primary organizing concept in children’s rehabilitation and some strands of disability studies. It generally understands progression from childhood to adulthood as a relatively predictable trajectory of achieving physical, intellectual, emotional, and social milestones. While this concept can be helpful in guiding rehabilitation practices, it can have some unintended harmful consequences for young people including those labeled with ‘developmental disabilities’, whose developmental and social trajectories differ from the norm. In this talk, I will discuss how taken for granted assumptions about ability as valued and preferred over disability, and normal developmental milestones as the markers of a ‘proper’ life course progression, orient rehabilitation practices to ‘normalizing’ function. While these practices can have positive effects, they can also have harmful consequences. Using examples from two critical qualitative studies, I will discuss the ways in which ablism and developmentalism underpin the aims of rehabilitation and explore their disabling and intersecting effects for young people with ‘developmental disabilities’. The first study interrogated the practices, policies and family experiences of rehabilitation services oriented to ‘transitions to adulthood’. The second study examined assumptions about disability and development underlying occupational therapy (OT) practices and their effects for young disabled adults through critical reflexive dialogues with a group of OT students, clinicians and researchers. The implications for rethinking the aims of rehabilitation and considering other possibilities for supporting young people labeled ‘disabled by their development’ will be discussed.

Reorienting constructions of concussion ‘recovery’ through a disability studies lens

Katie Mah, Gail Teachman

Western University, London, Canada

In this session, I make the case that the rehabilitation sciences, on their own, are ill-equipped to account for the complexity of youth concussion, and that engaging a critical disability studies lens opens up diverse ways of understanding concussion ‘recovery’. Despite an increasing moral urgency about how to prevent and treat concussion, little scholarship has been directed toward understanding what concussion ‘is’ (e.g., the social and political forces shaping how concussion is understood). Accordingly, youth concussion remains narrowly defined and centrally organized around its pathophysiology and clinical symptoms. When concussion is understood in relation to its effects on the biological body, it appears self-evident that how concussion is intervened upon be similarly organized. My research suggests, however, that concussion is not only a biological injury but also a social phenomenon that youth come to know in the social world, where pervasive discourses of vulnerability, risk, and responsibility abound, producing and constraining how youth are able to respond to concussion as ‘responsible’ subjects. Governing themselves in accordance

with expert knowledge, youth engage in intricate practices of monitoring and modifying their health, social interactions, and activities to return to their 'normal' pre-injury selves. This research suggests the need to investigate how normative ableist constructions of concussion recovery limit how 'successful' recovery is conceptualized, the supports and services that are developed and offered, and the possibilities for youth to make sense of their embodied experiences of recovery. I outline how engaging scholarship beyond the bounds of rehabilitation's ableist roots and normative practices, including Shildrick's ethic of openness, enabled me to reorient constructions of concussion 'recovery' in new and meaningful ways (e.g., recovery as living well with symptoms). Implications for rethinking the aims and practices of rehabilitation in relation to concussion recovery will be discussed.

Re-orienting childhood disability: Critical discourse analysis in the fields of disability studies and children's rehabilitation

Gail Teachman¹, Kelly Fritsch²

¹ *Western University, London, Canada*

² *Carleton University, Ottawa, Canada*

Dominant societal discourses situate childhood disability as a problem of individual children and their families, positioning childhood disability as a tragic burden to society. Such ubiquitous assumptions shape practices related to childhood disability in profoundly detrimental ways. Rehabilitation remains one of the most enduring societal responses to childhood disability and has conventionally placed emphasis on fixing or 'overcoming' individualized 'deficits'. However, this focus fails to acknowledge the societal norms and conditions that continue to constrain disabled children. In resistance, disability activists and scholars have long argued that disablement is a result of material, social, political and attitudinal barriers. Yet, relatively little research in disability studies has focused specifically on childhood disability and insufficient attention has been paid to how some of the assumptions and values underpinning disability studies can further marginalize some disabled children. In this talk, we share results from our critical discourse study that examined how childhood disability is conceptualized and acted on in the fields of disability studies and children's rehabilitation. Tensions between these fields have been perceived as irreconcilable and as a result, valuable knowledge has been siloed. Our study has explicitly aimed to bridge these disciplinary and political boundaries. We begin by providing an overview of our interdisciplinary study and share key results that focus on the social mechanisms, underlying logics, and organizing principles that structure these two fields. We then outline first steps towards the development of a set of guiding principles that can bridge these two important fields and help re-orient conceptualizations of childhood disability. These results demonstrate the tremendous potential for collaborating across disability studies and children's rehabilitation to catalyze policy and practice transformations that better enable the flourishing of all disabled children. We conclude by reflecting on how together the session papers productively move towards re-orienting rehabilitation and childhood disability.

11-05-2023

14:25 - 15:45 - **Culture and history I - The Secret Life of Bíbí in Berlín** ÖBÍ 2 - Sigtún 42 /

Bíbí in Berlín as a Counter-Archive

Sigurður Gylfi Magnusson,

University of Iceland, Reykjavík, Iceland

Bíbí in Berlín as a Counter-Archive

The the source material that belonged to Bíbí in Berlín (Bjarney Kristjánsdóttir 1927-1999) is filled with personal descriptions of her life. For example, in her autobiography she talks about the life on the farm, which was called Berlín, both her childhood and her adult years in another location. She also writes about her family and neighbours with a great sense of humour and irony. Bíbí wrote her autobiography, keeping it secret from her family and neighbours. Very few of them even knew that she could read and write, because after all she was from an early age labelled an “idiot”. The text is unusual and are mostly written in pencil and some of the words have been retraced so many times like she was trying to make sure that her story would not be forgotten. Bíbí’s story, both her autobiography and other kind of sources, will be analysed based on two research discipline, the critical disability studies, and the methods of microhistory. I plan to treat a very diverse source material that was part of Bíbí’s world as a counter-archive; political, resourceful, resistant, and community-based. Her counter-archive is embodied differently than regular archives and disrupt conventional national narrative. It is treated like a constructive critique that debunks hegemony and builds up or puts together a comprehensive understanding of the world. Her counter-archive is part of a defragmenting histories of her oppression. In the foreground will be the whole life span of hers, from the cradle to grave.

“In a very low mood” („Í skapi örgu.“)

Sólveig Ólafsdóttir,

University of Iceland, Reykjavík, Iceland

In the 1960 census, ten people were registered with residency in the nursing home a small town called Blönduós. Nine were born from 1869 to 1893. Bjargey Kristjánsdóttir (who had the nick name Bíbí) was born in 1927 or 34 years after the second youngest. In annals that dealt with her first ten years in the old age home – an unpublished book of poetry from 1968 – Bíbí describes residents and others, along with the nursing home staff, in great details. She also writes very emotionally about her inner life at the nursing home, but she moved there at the age of 30. The transition from her parents’ home to the nursing home was the biggest change in her life, a fundamental disruption of her daily life.

The concepts of emotions. emotional words and emotional communities come from the work of American historian Barbara Rosenwein and has been an important analytical tool when one studies the “life threads” – or the life stories – of disabled people in the past. In this

paper the plan is to focus on the transition, when Bíbí moved from her childhood home to a totally new location where she had almost no family ties. In short, just over night she lost her emotional community and was left on her own in a new location, away from everyone she knew in her life. The question is: how did she manage to build a new emotional community within the small town of Blönduós?

Growing a family: exhibiting the collection of Bíbí in Berlín

Guðlaug Dröfn Gunnarsdóttir,

University of Iceland, Reykjavík, Iceland

Bíbí in Berlin left behind an extensive doll collection of over 100 dolls, now preserved by the National Museum of Iceland. Registration and exhibition of the doll collection forms the foundation of this research. People's doll collecting is not uncommon and differs in aspects and origins. Bíbí dreamed of having a husband and children - a family. In her autobiography she writes about dreams that might have been and these dreams were to some degree expressed in making clothes for her dolls and gardening. She practiced these crafts not least during her stay in the retirement home as a young person and thus found an output for her life and dreams.

Bíbí's autobiography is a powerful tool that can be used to educate and alter attitudes. Thus, the importance of cooperation of disabled people and relevant groups when script making for intended exhibition as one must take a stand, include the subject, and strive for a truthful narrative. This presentation will discuss the registration and consequent research of Bíbí's dolls, doll collecting in a larger context and ways to envisage an exhibition about Bíbí, her material surroundings and her collection.

Young People in Old Age Homes in the 20th Century

Atli Þór Kristinsson,

University of Iceland, Reykjavík, Iceland

In the Icelandic media, a recurring type of story featured is one in which a young person with disabilities—or, at least, well below retirement age—has been placed in a retirement or nursing home, usually reserved for older adults. Frequently, a public outcry and calls for reforms follow, while the authorities name a lack of funding as the cause for the current state of affairs. How was the situation in the past, at a time when institutions such as old age homes were first being established in Iceland? In this talk, the main research findings on the history of placing young Icelandic people with disabilities in old age homes will be presented. The study has three main goals: First, to gain insight into how common this practice was, from around the time when the first homes were established in the 1920s to around the end of the 20th century. Analysing data from one of the oldest and largest home in Iceland, I conclude that well into the second half of the 20th century, the number of young people in old age homes was relatively high. The second goal of the study is to use a microhistorical approach to examine the life of a few individuals more closely, who were placed at a young age in homes of this nature and how was their daily experience. Finally, the general idea is

to see how this study can contribute to current policy debates on services for people with disabilities in Iceland.

11-05-2023

16:10 - 17:30 - **Inclusion I - Leisure and sports** Grand Hotel - Ásgarður /

Farm-based Daily Activities and Horses - Staging for Inclusion

Marie Gustavsson¹, Charlotte Lundgren²

¹ *Linköping University, Norrköping, Sweden*

² *Linköping University, Linköping, Sweden*

In Sweden, persons with significant and long-term functional disabilities are entitled to supplementary support (LSS 1993:397). Farm-based daily activities as well as horse related activities have traditionally been seen as beneficial for this group. In this paper we present and discuss findings from an ongoing study of daily activities for persons with intellectual/cognitive disabilities at two different settings where horses are an important part of the offering.

The aim of this paper is to analyse how an inclusive environment for persons with intellectual/cognitive disability can be staged - and restaged when threatened or questioned.

Data for this ethnographic study has been gathered through participating observations and interviews. Thematic analyses and interpretations of field notes and interviews has been done in relation to the theoretical framework of symbolic interactionism and especially Goffman's dramaturgical perspective.

The findings presented and discussed in this paper highlights *staging* for inclusion and competence. A stance which might be somewhat provocative to someone who do not understand how the metaphor of the theatre (Goffman 1959) can be deployed as a theoretical lens. We thus wish to stress that the daily activities and the work the participants carry out are real and make a real difference for people as well as horses. In this context, Goffman's idea of staging underlines is the importance of meaning making and socio-emotional practises when arranging and continuously re-arranging the practice in daily activities. To complement previous studies on horse related activities, this paper focuses on the importance of the environment, both physical and social environment, for the experience of participation, self-determination and inclusion for the participants in farm-based daily activities where horses have an essential role.

Mainstreaming the daily sport practice- Perceptions about inclusion of parasports on club level

Malin Andersson, Kim Wickman, Staffan Karp

Umeå University, Umeå, Sweden

This ongoing study investigates an organisational change aiming towards equal opportunities for people labelled with disability within the Swedish Sports Confederation. Through this change, parasports and athletes will be included in National Sports Organisations that are offering the same or similar sports, mainly for mainstream athletes. This brings new demands on the NSOs and their affiliated clubs concerning availability, such as physical access to practice venues, and special competence. The aim of this study was to investigate perceptions regarding challenges, opportunities, and sense of preparedness for the process on club-level. The analysis uses frame factor theory, and especially its dimension of patterns, referring to how actions and values in the daily sport practice are constantly reshaped and reconfirmed by the people in it. The data consists of an estimated 50 semi-structured interviews with para-athletes and their family members, mainstream athletes, coaches/leaders and elected club representatives from eight different clubs in four different sports facing this process. Preliminary results show an opportunity for the process to enable a stronger sporting identity for para-athletes by belonging to the mainstream-organisations. It also shows a low level of knowledge about the ongoing process, among both mainstream- and para-athletes, possibly leading to missed opportunities for all athletes to make informed decisions and making their voices heard on matters regarding their everyday-life in sports. The discussion focuses on enabling and limiting structures made visible through frame factor theory, and how they can influence a process towards equal opportunities in sports.

Stop with Special Solutions for Para Athletes - The Inclusion Process on Organizational level in Mainstream Sport

Kim Wickman, Malin Andersson, Staffan Karp,

Department of Education, Umeå, Sweden

A major organizational change is currently taking place in Swedish sports, with athletes labelled with disabilities leaving the Swedish Parasport Federation to participate in mainstream sports under the National Sport Organizations (NSO). This ongoing study is based on interviews with eight key stakeholders about the inclusion process of parasport into NSO. The informants were interviewed twice in 2020 and 2021. Drawing on frame factor theory, the study aimed to explore how the key stakeholders interpret, translate, and enact inclusion in sport. It brings knowledge about contextual conditions in terms of how goals and efforts were prioritized, organized, and distributed, and how values, knowledge and experiences were chosen and structured. The preliminary results indicated that the interviewees believed that most sports emerged in different social contexts and under different economic conditions than today. In order to ensure that NSO's conducts activities that meet a diversity of athletes, changes towards inclusion are necessary. However, there seem to be an inertia in the system that is difficult to get a hold of. According to contextual ideologies, the interviewees ask for transparency, systematicity and clarity according to the process for the change to be feasible. In terms of frames, the interviewees emphasized that new rules regarding economic and financial conditions including budget, buildings, staffing, facilities, and infrastructure, will also affect what is possible to do in practice. In sum, inclusion can be seen as a structurally and socially constructed activity and as a process occurring within limits of formal and informal values among the stakeholders.

Canada Games and the Inclusion of Athletes with Intellectual or Developmental Disabilities in Sporting Events

Nicole Luke¹, Avery Keith²

¹ *Brock University, St Catherines, Canada*

² , ,

Athletes with intellectual or developmental disabilities are often excluded from sporting events where able-bodied athletes are competing. Canada Games is one event where these athletes are included in some events. The aim of this presentation is to share direct experiences of individual athletes with developmental disabilities. A mixed methods approach was used to analyze the interview transcripts from athletes who shared their experiences of participating in track and field/athletics events. The results suggested the emergence of several important themes including friendships, confidence, a sense of belonging, and support for participating in an inclusive community that appear to have contributed directly to the perception of improvements in quality of life for the individual athletes and their families. These findings support the idea that participation in athletics may be an important avenue for improved quality of life in individuals with developmental disabilities.

11-05-2023

16:10 - 17:30 - **Culture and history I - The Secret Life of Bíbí in Berlín**
ÖBÍ 2 - Sigtún 42 /

- Moderator: Solveig Olafsdottir, University of Iceland
- Moderator: Guðlaug Dröfn Gunnarsdóttir, University of Iceland

The autobiography of Bíbí in Berlín in the light of reception theory and critical disability studies

Guðrún Valgerður Stefánsdóttir,

University of Iceland, Reykjavik, Iceland

The autobiography of Bíbí in Berlin (Bjargey Krijánsdóttir 1927-1999) was published in Iceland in the spring of 2022. The book immediately attracted great attention, including by Bíbí's relatives and the people who were part of her community. The reactions were mixed, both negative and positive. While some were happy to learn how, in fact, altogether Bíbí was, others were upset about what they read about relatives and friends and accused Bíbí of lying..I am going to make three main point is this paper: Firstly, interviews with Bíbí's relatives after her autobiography was published will be discussed; secondly, group interviews with people in the community Bibí lived for forty years will be conducted, and thirdly; material from the social media in Iceland will be gathered, where individuals expressed themselves about Bíbí's story. All this source material will be analyzed in the light of reception theory/reader response criticism and critical disability studies. By using reception theory, the goal is to emphasize each particular reader's interpretation in making meaning from the text.

Critical disability studies are, on the other hand, used to analyze how the discourse reflects negative historical beliefs and stereotypes of disability in the past and present and whether/how ableist vision of disabled people can be detected within the discourse.

Bíbí's life in transition: Uprooted in a new community

Helena Gunnarsdóttir,

University of Iceland, Reykavík, Iceland

The focus of this paper will be on the seventeen years that Bíbí spent in an old age home in Blönduós, a local community that was totally foreign to her. She was moved to Blönduós after her mother died, but Bíbí was 30 years old at the time.

The researchers in the collaborative study are four women with intellectual disabilities, whose role is to analyse Bíbí's story along with a non-disabled researcher. A framework of intersectionality is used to read into the life of Bíbí in the old age home. The purpose is to create a deeper understanding of her life and circumstances, draw out lessons from Bíbí's history and transfer them to the position of women with intellectual disabilities in the present day. We will focus on how Bíbí managed to find her niche in life and fight all kinds of difficult situations that she faced as a young woman on an everyday basis during her stay in the old age home. The women in the research group will describe their experience of participating in the research project and how the process affected them.

The value of life story work with people with learning disabilities

Liz Tilley, Jan Walmsley, Nathaniel Lawthorn

The Open University, Milton Keynes, United Kingdom

In this presentation we will give a brief history of life story work with people with intellectual disabilities. We will first consider the role of life story research in developing knowledge about the wider history of learning disability, and how life story methods continue to be a critical mechanism for supporting inclusive approaches to history (this issue will be explored in more detail in our second presentation, led by Nathaniel Lawthorn).

Drawing upon our recent review of the literature, we will explain the value of life story work and how it can benefit people with intellectual disabilities in their everyday lives. We will use examples from our research to share different approaches to life story work, including the use of digital programmes and emerging visual formats such as Manga. The presentation will also explore why life story work has proved difficult to embed as part of routine practice in health and social in the UK, despite a growing body of evidence highlighting its value.

Activist history, autobiographies, and life story work with people with learning disabilities - using history and stories for social change

Nathaniel Lawthorn, Liz Tilley, Jan Walmsley

The Open University, Milton Keynes, United Kingdom

How do people with intellectual disabilities and / or autism use history to campaign for change?

In this session activist historian Nathaniel Lawthorn will explore with Jan Walmsley and Liz Tilley what it means to be an activist historian. Nathaniel will explain how he got involved with this work, and how his own, and other self-advocates' life stories inform his activism.

Nathaniel will then challenge Jan and Liz to explain and justify their roles as academic historians. We will also consider the ethics of asking people to reflect upon often traumatic life experiences as they tell their stories.

11-05-2023

16:10 - 17:30 - Human rights I - Anti-discrimination and rights promotion Grand Hotel - Hvammur

Public procurement, human rights and anti-discrimination in special transport services for people with disabilities in a Swedish and EU context

Pettersson Andreas,

Södertörn University, 14189 Huddinge, Sweden

This is an exploratory paper on preliminary findings from the application of a model for legal analysis developed within a research project on the right to everyday transport for children and young people with disabilities in Sweden. The model shows that normative regulation of public transport for people with disabilities can be categorized into three broad fields: anti-discrimination norms for persons, anti-discrimination norms for traffic, and anti-discrimination norms for public procurement. The primary purpose of anti-discrimination norms for persons and traffic is compensatory measures aiming towards equal treatment of people with disabilities. The primary purpose of anti-discrimination norms for public procurement is equal treatment of transport companies.

The normative regulations come from different legislative levels: CRPD, EU law, national law, and more specified regulations and guidelines from national public authorities. The model shows that anti-discrimination norms for persons exist almost exclusively in an overall fashion in international law and national law, while anti-discrimination norms for traffic and public procurement exist on all legislative levels. This suggests that anti-discrimination norms for traffic and public procurement are more specified and more pinpointed towards specific problems compared to the overall anti-discrimination norms for persons. A tentative conclusion is that the public procurement norms are the strongest form of regulation for public transport for people with disabilities.

The supervision is weak concerning anti-discrimination norms for persons, stronger for anti-discrimination norms for traffic, and very strong for anti-discrimination norms for public procurement. This is important for the practical application of law and suggests that given choices between anti-discrimination of persons and companies, respectively, anti-discrimination of companies may become more important.

Rights in practice: a reflection on Uganda's progress in implementing the right to accessibility, education and employment for persons with disabilities

Patrick OJOK,

Kyambogo University, Kampala, Uganda

Uganda signed the United Nations Convention on the Rights of Persons with Disabilities on 30 March 2007, and ratified both the Convention and its Optional Protocol on 25 September 2008. As required under Article 35 of the CRPD, Uganda submitted its Initial Status Report to the UN Committee on the Rights of Persons with Disabilities in 2013. The UN Committee on the Rights of Persons with Disabilities considered Uganda's initial status report and provided the concluding observations and recommendations in 2016. The committee made several observations on areas of strengths and made recommendations to address outstanding gaps. Uganda has prepared and is in the process of submitting its second, third and fourth periodic reports that were due by 25 October 2022. Using the UNICEF Scale for policy analysis as the analytical framework, this paper undertakes a critical analysis and provides a snapshot of Uganda's overall progress in implementing the Convention since submitting its initial status report. The paper then delves into an in-depth analysis of the implementation status of three CRPD articles, namely: accessibility (article 9), education (article 24) and work and employment (article 27). Preliminary analysis show that overall, the country is on the right track in terms of domesticating many provisions of the Convention but is yet to review certain laws modelled on the colonial legacy that discriminate on the basis of disability. Accessibility remains a major barrier in the workplace and educational institutions partly because the laws are neither enforced by the state nor utilized by the persons with disabilities experiencing access barriers. The paper concludes with a discussion of the contextual factors hindering the realization of the Convention in relation to accessibility, education and employment, and proposes actionable measures to reinvigorate implementation.

Investing in social inclusion - challenges and opportunities that EU Structural Funds bring in the implementation of Article 19 of the UNCRPD

Magdi BIRTHA,

European Centre for Social Welfare Policy and Research, Vienna, Austria

EU funds contribute significant resources to social inclusion, especially in Central-Eastern European Member States. During the past EU funding periods, problematic areas of investments from the human rights point of view were identified, including settings, infrastructure, or services that segregate, or discriminate different groups of people (e.g., persons with disabilities, children, Roma etc.). The Common Provisions Regulation for the EU funding period 2021-2027 requires Member States to ensure the EU Charter for Fundamental Rights and the UN Convention on the Rights of Persons with Disabilities (CRPD) are respected throughout the programming period. Since the EU and all its 27 Member States ratified the CRPD, it is of key importance that EU funds contribute to the progressive implementation of the Convention, through empowering persons with disabilities, improving their access to goods, services, and to the labour market.

This paper provides an overview of the current challenges and bottlenecks when it comes to assessing EU funded projects' compliance with Article 19 of the CRPD, and analyses in a holistic way how disability rights could be better respected in the current EU funding period, with special regard to the role of different stakeholders (European Commission, governments, National Human Rights Bodies, civil society). The paper is building on a systemic analysis of available academic literature, legislative and non-legislative documents, complaints and inquiries of the European Ombudsman, policy papers and reports prepared by public authorities, international organisations, and civil society organisations (grey literature). Through the horizontal enabling conditions, the present regulation provides a strengthened framework to monitor the compliance of EU funded investments with CRPD provisions. Nevertheless, a deeper understanding of the root causes and impact of misuse in the past is necessary, along with identifying what could be done at different policy levels, to ensure the full social inclusion of persons with disabilities.

Disability and Sex Rights: Recognizing Sexual Citizenship

Roxanne Mykitiuk¹, Isabel Karpin²,

¹ *Osgoode Hall Law School of York University, Toronto, Canada*

² *University of Technology, Sydney, Ultimo, Australia*

Persons with disabilities are often regarded by others, including their family members, teachers, support workers and healthcare providers, as asexual. As a result, they are often excluded from a range of experiences, practices and services that would protect and promote their sexual citizenship and secure their meaningful inclusion and participation in society.

This paper explores the dimensions of sexual citizenship for persons with disabilities as a matter of human rights law and examines both the fundamental human rights values upon which a concept of sexual citizenship can be underpinned and the international instruments upon which it can be secured, including grounding the discussion in the relevant articles and commentaries of the *Convention on the Rights of Persons with Disabilities* (CRPD). Domestic sources of law will also be canvassed where relevant from Canada, Australia and the Nordic countries, in addition to less liberal regimes.

The paper will argue that the rights of persons with disabilities to sexual citizenship includes the right to: exercise and express sexuality freely (including assistance with sexual activity as a form of accommodation if necessary (including access to sex workers and/or facilitation from care providers); consent to sexual activity; be safe from sexual abuse and discrimination; be educated about and have access to sexual and reproductive health information and services; make informed decisions about one's own body; and, if one choose to do so, to experience parenting. The paper, examines the barriers and stereotypes that persons with disabilities encounter in participating in sexual and [reproductive] activities, ensuring accessible sexual education and reproductive health services and parenting supports and services. We explore the role of the state in simultaneously facilitating and restricting access to sexual citizenship for persons with disabilities and the implications for rights recognition and enforcement.

11-05-2023

16:10 - 17:30 - **Policy and theoretical perspectives I - Disability within (inter)national contexts** Hilton Nordica meeting room F /

Disability Pensions/Benefits Systems in Israel and abroad: An international comparison

Nitsan Almog¹, Gal Zohar²

¹ *Ono Academic College , Kiryat Ono, Israel*

² *Israeli Public Employment Services (IES), Jerusalem , Israel*

Background: During the last four decades, the attitude towards people with disabilities has slowly shifted from a medical approach to a social approach. Such shift is reflected by legislation processes worldwide (and later in Israel) and by developing new models for measuring and assessing disability, including the ICF. Nowadays, most countries updated their disability benefits systems, vis-à-vis the ICF framework. However, embracing this approach compelled us to identify the local context within which the social approach is being diffused.

Methods: The current study compares the disability benefits systems for people with disabilities in six different countries (Finland, UK, Canada, Taiwan, Denmark, and Norway) to the disability pension in Israel. Through an in-depth comparison of the benefits systems and the disability typologies, a process-tracing of national reforms was conducted.

Findings: Findings indicate that in the last two decades, all countries reviewed apart from Israel included different functional and social parameters in their disability assessment processes. The existing benefits systems in Israel are like the ones in other countries. However, when we start to examine the disability assessment process and the conditions associated with receiving the benefit, we find significant differences between Israel and other countries. Specifically, the complete disability policy surrounding the pensions eco-system is complex and affected by the type of benefits systems, disability assessment processes, and activation stance. It is this triple framework of the disability pension systems which is well needed to apply a genuinely inclusive approach.

Conclusions: A renewed application of functional and societal tools in disability assessment processes should manifest differently according to each country's type of benefits and systems vis-à-vis the existing links between disability benefits and rehabilitation services.

People with profound intellectual and multiple disabilities (PIMD) – a binational comparison (Germany/Sweden) on school education and housing in adulthood

Torsten Dietze¹, Joana Debelt², Jenny Wilder², Tobias Bernasconi¹,

¹ *University of Cologne, Cologne, Germany*

² *Stockholm University, Stockholm, Sweden*

In the international discourse - also on the part of the IASSIDD - the group of people with profound intellectual and multiple disabilities (PIMD) is described as a „*heterogeneous group [...] characterized by very severe cognitive, neuromotor and/or sensory disabilities, which lead to very intensive support needs*” (IASSIDD / SIRG PIMD, 2022, see:

<https://iassidd.org/sirgs/profound-intellectual-and-multiple-disabilities/>).

In a binational comparison, Germany and Sweden will be examined concerning current basic societal structures as well as current developments in disability policy in the field of PIMD. The focus lies on cultural and structural similarities and differences in the issue of "labeling" or conceptualization (Granlund et al, 2013) of PIMD in two selected fields: school education and housing in adulthood.

Using source research in relevant legal regulations and enriched by results of a research assignment (Germany) and first findings of a running doctoral project (Sweden) the following questions are addressed:

What policy and legal nation-specific regulations frame the labeling and work with people with PIMD in the two selected fields of action?

What are the national /and federal systems for providing support for the work with people in the field of PIMD?

Which differences are there in the discourse around "capabilities and expectations" (Bernasconi 2016, Vehmas & Mietola 2021) in social discourses, and are concepts such as capability approach deposited as strategic goals in national disability policy?

The presentation wants to contribute to the field of research concerning the specific group of PIMD and encourage for intradisciplinary as well as interdisciplinary research and action research.

Literature

Bernasconi, T. (2016): Bildung bei schwerer und mehrfacher Behinderung. In: *Teilhabe* 55 (4). 168-172

Granlund, M. & Wilder, J. & Almqvist, L. (2013). Severe Multiple Disabilities. The Oxford Handbook of Positive Psychology and Disability. 452-474.

Simo Vehmas, Reetta Mietola (2021): *Narrowed Lives. Meaning, Moral Value, and Profound Intellectual Disability*.

Critical analysis of influential policy and guidelines in Armenian rehabilitation: What are the prevailing assumptions about disability and implications for disabled people in Armenia?

V. Armineh Babikian, Yani Hamdani

University of Toronto, Toronto, Canada

Following the 2020 Nagorno-Karabagh War, the disabled population in Armenia increased significantly as a result of complex physical injuries and psychological trauma. Rehabilitation services were already supporting people with developmental disabilities, survivors of natural disasters, and injured soldiers from previous conflicts. However, the recent events highlighted systemic gaps in sufficiently supporting the recovery and quality of life of this growing population, resulting in a shift in national priorities. In 2021, the Armenian parliament adopted the law on Rights of Persons with Disabilities to protect against discrimination and social exclusion, and the Ministry of Health invited the World Health Organization (WHO) to advise on health system strengthening of the rehabilitation sector. WHO recommended several priorities, including the need for governance, leadership, and policy frameworks to

guide rehabilitation service planning and design. Although WHO advises that the State, health service providers, and service users interact for effective health system governance, disability self-advocates (DSAs) in Armenia report being excluded from healthcare reform, counter to the newly passed law promoting social inclusion. Moreover, Armenian DSAs advocate for a human-rights approach rather than a medicalized approach, thus their priorities may not be addressed through the newly implemented WHO framework, the International Classification of Functioning, Disability and Health. Discourses of disability underpinning national rehabilitation planning and design may not align with disabled people's priorities and wishes for help and support. Guided by Bacchi's What's the Problem Represented to be? approach (2016), I examined discourses and assumptions about disability underlying Armenian policies and WHO guidelines informing rehabilitation planning and design and the implications for disabled people in Armenia. In this talk, I will discuss the potential beneficial and harmful consequences for disabled Armenians when these discourses guide rehabilitation development, and propose ways to rethink the aims of rehabilitation through co-design with disabled people and a human-rights lens.

Decolonising disability studies: Too much theory, or not enough?

Leslie Swartz,

Stellenbosch University, Stellenbosch, South Africa

There are many calls for disability studies to 'decolonise' and to pay attention to issues of historical and current exclusion. Some argue that since the advent of the social model, the agenda of the discipline has been implicitly decolonising, but there remain questions about the dominance of the global north in disability scholarship and theory, when there are a disproportionate number of people with disabilities in the global south. These people have been deeply affected by (post)colonial issues.

Along with the high rates of impairment associated with extractive colonial economies, other patterns of exclusion have been established, and remain. People with disabilities are commonly excluded from education and employment opportunities and are not part of the conversations and policy-making which affects their lives.

Many interventions have been made by disability scholars to create a more inclusive disability studies, and to help the field act more globally. Many of these have been couched in language strongly influenced by critical social sciences and not always easily accessible to people outside these disciplines, and to people who do not speak English as a first language.

Drawing on my experience of working with disabled people's organizations in southern Africa and as a journal editor and academic based in South Africa, I use this presentation to think through some of the dilemmas associated with decolonising disability studies. Many of the debates centre on the relationship between theory (often developed in the global north) and the lived experience of people with disabilities in marginal circumstances in the south. There are a number of potential pitfalls associated with decolonising disability studies, falling in a continuum from retreat into theory on the one hand and retreat from theory on the other. These tensions are not easily resolvable but they need to be thought about and borne in mind.

11-05-2023

16:10 - 17:30 - **Inclusion II - Methodology** Grand Hotel - Útgarður /**The accessible language paradox in co-produced disability research: insights from a group biography**Javier Monforte¹, Brett Smith²¹ *Universitat de València, Valencia, Spain*² *Durham University, Durham, United Kingdom*

Co-producing is a valuable way of researching disability matters. Over the last three years, we have been developing a co-produced project in which disabled people and disability organisations (e.g., Disability Rights UK) have played a central role. The purpose of the project was to train social workers on how to support the rights of the UK's 14 million disabled people to fully participate in physical activity on an equal basis with others. We called it *Moving Social Work*. We assembled a co-production group: The Moving Social Work Collective. What for? Who was involved in the group? What was it like to be involved? To answer these and other questions, we conducted a group biography. In this presentation, we first provide an original conceptualisation of the group biography approach. Following from this, we draw the attention to the content of the group biography we conducted. In this occasion, we focus on one of the issues that caused a breakdown in our understanding of co-production. We shall call it the accessible language paradox. What do we mean by this label? What in the co-production process made us think about it? How can we interpret the accessible language paradox from a disability studies lens? Which are the implications of this paradox for doing co-produced research with disabled people? Our presentation will provide modest responses to these questions, hopefully sparking discussions on to conduct more democratic research moving forward.

The use of 'small stories' to extend the boundaries of inclusive research to people with people with profound intellectual disabilities

Catherine De Haas,

University of Southampton, Northwich, United Kingdom

How can the experience of community of people with profound intellectual disabilities be made into text in a PhD thesis? People with profound intellectual disabilities communicate with people who know them well without words. I will approach this challenge by using 'small stories' constructed ethnographically with the people with profound intellectual disabilities and their families. In this presentation, I will illustrate my plan by using 'small stories' from my own experience of living for 31 years with my daughter, Johanna who had profound intellectual disabilities. We created intersubjective knowledge together, which I used to enable us to belong to our own community as a family. She taught me the importance of 'being together'. How can I extend this so that the voice of people with PIMD can be accommodated in inclusive research culture? My field work will take place outside service provisions, in the places that people with profound intellectual disabilities access with their

families. I will have collaborative conversations with families using an informal focus group approach; this will lead to a collection of 'small stories' that families share with each other about their day-to-day experience of belonging to their own communities with their child with profound intellectual disabilities. Through these conversations, we will work out together how to strengthen their connections to each other and their own communities. People with profound intellectual disabilities have different ways of seeing. To access their knowledge of the world, I will go deeper than visual observation and use a deep awareness of the sensory difference of people with profound intellectual disabilities, and an openness to experience the world from their perspective. Importantly, this includes being affectively aware of the situation. I ask for your help as I rise to this methodological challenge.

Advancing research with and by children with disabilities

Janet Njelesani,

New York University, New York City, United States

Background

Children with disabilities have the right to participate in research so their priorities, needs, and experiences are included. Research based primarily on adult report risks misrepresenting children with disabilities and their needs and contributes to exclusion and a lack of diversity in the experiences being captured. Prioritizing the participation of children with disabilities enhances the relevance, meaningfulness, and impact of research.

Methods

A scoping review was conducted to critically examine the participation of children with disabilities in health research. The electronic databases PubMed, PsychInfo, Embase, and Google Scholar were searched. Inclusion criteria included qualitative health studies conducted with children with disabilities, published between 2007 and 2020, and written in English. Articles were screened by two reviewers and the synthesis of data was performed using numeric and content analysis.

Results

A total of 62 studies met inclusion criteria. Rationales for including children with disabilities included child-focused, medical model of disability, and disability rights rationales. Participation of children with disabilities in research was limited, with the majority of studies conducting research *on* rather than in partnership *with* or *by* children. Research *on* children typically did not include children as active participants but rather collected information through interviewing adults. Research *with* and *by* children engaged children using verbal, visual, and participatory methods.

Conclusion

This review provides a novel assessment of the current state of inclusion and the actions that could be employed to further advance the participation of children with disabilities in health research. Further effort should be made by researchers to incorporate children with a broad range of impairments drawing on theory and methodology from disability and childhood studies and collaborating with people who have expertise in these areas. Furthermore, an array of multi-method inclusive, accessible, adaptable, and non-ableist methods should be available to enable different ways of expression.

Intersectional Invisibilities: Reflections on the Inclusion of Marginalized Disabled Populations in Qualitative Research

Stella Chatzitheochari, Angharad Butler-Rees,

University of Warwick, Coventry, United Kingdom

Recent years have witnessed an increasing interest in intersectional disability studies. We have seen a move away from sociological narratives that adopt monolithic understandings of disability towards frameworks that place its intersections with other ascriptive inequalities at the forefront. However, intersectional empirical research on disability remains scarce: Existing large-scale studies usually provide insufficient numbers of disabled young people that do not allow robust estimation of intersectional effects, while qualitative studies face manifest difficulties in recruiting disabled people with other marginalized identities such as ethnic minorities and those from low social class backgrounds. This has meant that the vast majority of research has centered on relatively advantaged disabled populations, offering little insight surrounding intersections with other axes of inequality. This is an important omission given the potential of qualitative accounts to shed light onto the mechanisms implicated in the production of disability-related inequalities among marginalised groups.

This presentation will offer insights surrounding recruitment of marginalized disabled populations in qualitative research. We will draw on our experiences from 2 ongoing research projects: The Educational Pathways and Work Outcomes of Disabled Young People research project (2020-2023), funded by the Leverhulme Trust, and the Intersectional Effects of Disability and Social Class on Becoming NEET British Academy small research project (2022-2023). Both projects sought to understand the intersection of disability status with socio-economic disadvantage in the lives of young people in England. In this presentation, we will discuss issues surrounding gaining access, gatekeepers, online recruitment, use of incentives, and accessibility, and how these were used to recruit young people from socially disadvantaged backgrounds. We will also reflect on the strengths and weaknesses of prospective and retrospective research designs that can facilitate recruitment of populations typically invisible in existing sociological research.

11-05-2023

16:10 - 17:30 - **Education I - Higher education and academia 3** Grand Hotel - Muninn /

A tool for empowerment: Co-creation of the curriculum

Laufey Elísabet Löve,

University of Iceland, Reykjavík, Iceland

The right of disabled people to participate in the development of policy that affects their lives is at the heart of the Convention on the Rights of Persons with Disabilities (CRPD) and is fundamental to achieving its goal of full and effective participation of disabled people in society. Co-production of policy at all levels has been identified as essential to realizing this

goal. The research that this presentation is based on highlights the importance of ensuring that the right to participation and co-production is recognized as part of the development of a progressive rights-based education curriculum in a field such as that of social educators, who as professionals work to support the rights and active participation of disabled people. This is particularly relevant in the case of people with intellectual disabilities who, as research has shown, often have limited opportunity to effectively express concerns and interests specific to their lives and circumstances within disabled people's organizations (DPOs). This reflects what has been identified as 'hierarchies of impairment', where people with intellectual and psychosocial disabilities are often the ones on the lowest rungs of the hierarchy and, thus, in a marginalized position within these movements.

This presentation draws on a qualitative study that aimed to develop a platform for the co-production with people with intellectual disabilities of the curriculum of a course taught in the Department of Social Education at the University of Iceland. The data, collected in 2021-2022, consisted of focus groups and in-depth interviews, as well as document analysis of reports. The findings of the research resulted in changes to the curriculum based on the insights and understanding drawn from the lived experience of people with intellectual disabilities in areas that had previously been overlooked in the curriculum.

The lecturer perspective: student disclosure and non-disclosure of disability in teaching situations

Rannveig Beito Svendby,

Inland Norway University of Applied Sciences , Lillehammer, Norway

This paper draws on a qualitative, explorative study about lecturers' experiences of teaching disabled students in Norwegian institutions of higher education (Svendby, 2020). The study's aim is to produce knowledge that hopefully will inform practice and increase disabled students' opportunities to participate in learning situations.

In Norway, the government has an ambition of offering higher education to the whole population. Legislation and policies establish that higher education is to be accessible to all students 'within reason' (NOU, 2020; Universitets- og høyskoleloven, 2005). However, disabled students experience barriers in encounters with the system of higher education. It is a finding in the Norwegian research literature that students often end up accommodating for inclusion by their own account.

In this presentation, I use two empirical examples from the study as points of departure to reflect on different ways in which student disclosure and non-disclosure of disability may influence the creation of an including learning environment from the lecturer perspective. The cases are selected because they illustrate two different approaches to inclusion in learning situations, one based on disclosure and one based on non-disclosure from the student. The presentation reflects on how the teacher (study participant) approached the two different situations and how her approaches influence the potential of inclusion and learning by the group. Sociocultural approaches are used as a theoretical basis to inform the empirical data.

References

NOU 2020:3. (2020). *Ny lov om universiteter og høyskoler*. [New Act relating to universities and university colleges]. Retrieved from: <https://www.regjeringen.no/no/dokumenter/nou-2020-3/id2690294/>

Svendby, Rannveig. 2020. "Lecturers' Teaching Experiences with Invisibly Disabled Students in Higher Education: Connecting and Aiming at Inclusion." *Scandinavian Journal of Disability Research* 22 (1): 275–284. doi:10.16993/sjdr.712.

Universitets- og høyskoleloven. (2005). *Lov om universiteter og høyskoler*. (LOV-2005-04-01-15). [Act relating to universities and university colleges]. Retrieved from: <https://lovdata.no/dokument/NL/lov/2005-04-01-15>

Experiences of university students engaging in an online disability awareness program

Rebecca Barton¹, Monique Schoebel¹, Kim Bulkeley¹, Ilektra Spandagou¹, Michelle Bonati²

¹ *The University of Sydney, Sydney, Australia*

² *State University of New York Plattsburgh, Plattsburgh, United States*

Despite disability affecting approximately 15% of the world's population, negative societal attitudes towards disability persist impacting the participation and wellbeing of people with disability. These assumptions and stereotypes are often ingrained and difficult to change. In response, efforts have been made to develop education programs that aim to raise awareness of disability and address some of these negative attitudes. Despite a growing number of these programs, there is limited research exploring their effectiveness and the experiences of those who participate in them. Therefore, the purpose of this study was to investigate the perspectives and experiences of university students who participated in an online disability awareness program. This presentation reports on a mixed-methods study involving a survey and in-depth interviews used to gather the perspectives of university students who had engaged in an online disability awareness program developed at the University of Sydney. Emerging results indicate that experiences varied in relation to personal factors of participants. A relationship was identified between two key themes: perceived impacts of the program and the effective and engaging features of the program. The nature of the program's online, self-paced, multi-modal design, which included videos of people with disabilities sharing their lived experience, promoted positive change in disability awareness and responsiveness. Participants reported that the online program improved their knowledge around disability which further developed their confidence to engage with people with disability. This study is the first to contribute an Australian perspective to emerging research around the effectiveness of online disability awareness programs for university students.

Barriers to people with disabilities becoming academics

Jonathan Levitt, Mike Thelwall, Felipe Moreira

University of Wolverhampton, Wolverhampton, United Kingdom

In this presentation we will report some early findings from our project, 'Disability-related barriers to obtaining academic employment', which is described at <http://cybermetrics.wlv.ac.uk/disabilitysurvey.html>. The focus of our project is to identify

disability-related barriers to academic employment and how these barriers could be addressed. We recently published a comment piece that draws on our experiences on this project in Nature Human Behaviour ('How we can make academia more disability inclusive', 2022).

In this current presentation, we will consider some of the key findings from our survey of academics. These academics had: (a) published one or more Web of Science indexed articles or reviews with 'disab' in the title between 2010 and 2018, and (b) provided a '.ac.uk' or a '.edu' contact email address. 235 of the survey respondents indicated that they had disabilities, 611 indicated that they did not have disabilities and 223 used UK contact email addresses. The responses were classified according to type of barrier, and the frequencies of each type of barrier were evaluated. Eighteen different types of barrier were identified.

The two most frequently expressed types of barrier were attitudes to people with disabilities (Attitudinal barriers) and barriers that can be addressed through reasonable adjustment by academia (Adjustment barriers). Other types of barrier mentioned in published research on barriers to employment include Communication barriers, Educational barriers, Environmental barriers, Policy barriers and Social barriers.

These findings apply both to the respondents from British universities and to the respondents from American universities. Since many of the barriers seem to be addressable by universities, there is substantial potential for increased inclusivity in this regard. In our presentation we will consider ways in which academia and staff with disabilities can work together to help reduce disability-related barriers to employment.

11-05-2023

16:10 - 17:30 - **Disability and the lifecourse I - Learning Disability and Autism Research at Manchester Met** Hilton Nordica meeting room H /

Inside out: The experience of being PPI Coordinator and family carer on the Flourishing Lives and Growing Older projects

Angeli Vaid,

Oxfordshire Family Support Network, Oxford, United Kingdom

The aim of this paper is to encourage researchers and their teams to hold the door wide open for family carers and people with learning disabilities to take part in research. Key learning points from both projects will be offered as part of a growing body of evidence for what good involvement can be in research projects of this kind.

Research funders increasingly request or require public and patient involvement in the development and delivery of research. Whilst few researchers would disagree with this, not all feel confident or competent to do this well. Family carers of people with learning disabilities face multiple and significant barriers to be involved in research despite sometimes being in a strong position to share the reality of living with learning disability and what they and their families need to live a good life.

This presentation will be from my perspective as a PPI Lead for these two research projects, new to social sciences research, but with decades of family carer experience. I will identify the barriers and facilitators I experienced in my role and how I dealt with these.

Using a model of the research cycle/pathway, I will share practical examples of how family carers and people with learning disabilities were involved at every stage. I will look at what worked well and why, what almost worked and what did not work at all. I will also share how we gathered the experiences of parent carers, people with learning disabilities and staff support team in the final stages of the project and personal impacts it had.

Experts by Experience on the Flourishing Lives and Growing Older projects

Pam Bebbington, Dawn Wiltshire, Lisa Davidson

My Life My Choice, Oxford, United Kingdom

Experts by Experience, Pam Bebbington and Dawn Wiltshire (with support of Lisa Davidson), speak about their experiences of the Flourishing Lives and Growing Older projects.

In their presentation, they draw from their personal experiences and the experiences of their friends on learning disabilities, challenging behaviours and growing older and about how these labels have ruled their lives. 'Challenging behaviours,' or 'behaviours that challenge' as Pam and others prefer to call it, is a label that has controlled the majority of their life: from relationships to stays in inpatient services and more. This presentation is also based on interviews with people with learning disabilities, and professionals from social care.

In this presentation, they will also share their experiences of working in a team made of people with learning disabilities, family carers, academic researchers and more. They'll talk about how they did it, what they learned and share their tips of how inclusive research projects can be done in an accessible way.

The transition assemblage: using Deleuze and Guattari to reconceptualise transition to adulthood for young people with learning disabilities

Francesca Ribenfors, Sue Caton, Leanne Rimmer

Manchester Metropolitan University, Manchester, United Kingdom

Transition to adulthood for young people with learning disabilities is conceptualised within UK policy as occurring between the ages of 14-25. It is a period when young people transfer

to adult services and professionals working within education, health, and social care settings, provide support to enable the young person to prepare for adulthood. Despite a plethora of good practice guidance, policy interventions and research attending to transition, it is a difficult time for young people and their families and remains rooted in exclusionary Western notions of child development and adulthood. Adopting a qualitative approach, this research explores the perspectives of those involved in transition: young people with learning disabilities, parents, and professionals. Three focus groups and 18 interviews took place with 36 participants. The themes generated from the data, using reflexive thematic analysis, highlight the complexity of transition demonstrating it to be a multidimensional, interconnected, and turbulent time for young people and their families contrasting with the 'transition pathway' imagery often promoted by social care services. As a result, and influenced by new materialism and critical disability studies, the work of Deleuze and Guattari is drawn on to present an alternative approach to transition. Transition is reconceptualised as an assemblage and a time to enable becomings rather than a time to 'transition people to adulthood'. This has the potential to improve individual experiences on a practical level whilst simultaneously acting as a form of conceptual activism and disrupting the normative foundations of transition which position young people with learning disabilities as different.

Choice, a slippery concept for people with learning disabilities moving house in supported living and residential care.

Francesca Ribenfors¹, Chris Hatton¹, Lauren Blood², Anna Marriott², Lucy Dunstan³, Siraaj Nadat³

¹ *Manchester Metropolitan University, Manchester, United Kingdom*

² *National Development Team for Inclusion, Bath, United Kingdom*

³ *Changing Our Lives, West Midlands, United Kingdom*

Article 19 of the Convention on the Rights of Persons with Disabilities states that people with disabilities have a right to choose where they live and who they live with. However, the inflexibility of traditional residential or group homes have made realising this right difficult. Supported living models, on the other hand, where housing and support are provided separately, are meant to afford people with learning disabilities greater choice and control as the person can change their support provider without their housing being affected and vice versa.

Drawing on data from a recent cross sectional, mixed-methods study involving 107 participants with learning disabilities living in supported living and residential homes in England, we examine the concept of choice. How much choice did people with learning disabilities feel they had over where they lived and who they lived with and, what differences, if any, exist between the housing rights people in supported living have compared to people living in residential group homes. The research shows that despite what people want from a house changing as their aspirations change, the current system focuses more on reactive moves, where people move only if there is a problem with their current home. Choices were restricted and often illusory with many people in both supported living and residential care not having the opportunity to look at different homes before they moved. The research has implications for both support providers and commissioners; commissioning strategies based on 'service model' will not guarantee a particular type of experience or support. Furthermore, there needs to be a greater emphasis on supporting people to consider, plan for and have choice over who they live with and where they live, both currently and in the future.

11-05-2023

16:10 - 17:30 - **Childhood disability I - Children's Rights and Disability** Hilton Nordica meeting room D /

- Moderator: Anne-Marie Callus, University of Malta

The Rights of the Child When Symbolic Language is Out of Reach

Bronagh Byrne¹, Kristin Vindhol Evensen²,

¹ *Queen's University Belfast, Belfast , United Kingdom*

² *The Norwegian School of Sport Sciences, Oslo, Norway*

The United Nations Declaration of Human Rights, the United Nations Convention on the Rights of the Child, and the United Nations Convention on the Rights of Persons with Disabilities enshrine that all humans are entitled to the same rights. The need for specific conventions for children and people with disabilities clarifies that rights cannot be taken for granted for minority groups. This presentation considers the right of freedom of expression on three levels: at the level of the Conventions, in research, and how it might have effect in the everyday life of children with severe and multiple disabilities.

This presentation has its point of departure in an embodied phenomenological perspective. Disability is understood through lived experiences, where every person is considered an embodied being enveloped in space, in time, with objects and in relation to other people. Thus, a fundamental principal of embodied phenomenology is to credit experiences as fully worthy, no matter the point of departure of the experiencing person.

What can be learned from the relationship between conventions, research and lived examples is that the right to freedom of expression applies to all children, everywhere, at any time. The right to freedom requires that childhood with disability is treasured as fully worthy, that embodied outreaches are accredited as expressive, and that significant others are continuously curious when interacting and interpreting embodied signals of a child with SMD.

This presentation enhances that there is a close connection between embodiment and freedom of expression as a human right for children with SMD. All humans are entitled to the same value in the UDHR, CRC and CRPD. The fact that embodiment is unmentioned in the conventions might mean that it is acknowledged as expressivity in a human continuum as well as meaning a neglect of its importance.

An Analysis of the UNCRPD Concluding Observations on the Rights of Children with Disabilities

Anita Franklin,

This presentation will explore the emergent foci of the rights of children with disabilities at the international level. Using Article 7 of the UN Convention on the Rights of Persons with Disabilities (CRPD) as the primary normative framework, the presentation engages a critical policy analysis of CRPD Concluding Observations on countries examined 2011-2020. It

identifies common patterns across States parties in terms of the most pressing issues of the time and the most significant barriers to implementation of children with disabilities' rights. The chapter concludes by reflecting on the extent to which the CRPD to date has advanced discussion and discourse on the intersectionality of disability and age.

The Care Dependency Grant in South Africa: Challenges on the (long) road to inclusive rights

Tammy Bachrach¹, Zara Trafford²,

¹ *Azusa Pacific University, Azusa, CA, United States*

² *Stellenbosch University, Stellenbosch, South Africa*

Both the United Nations (UN) Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD) assert the right of the disabled child to social protection and an adequate standard of life. In South Africa, an early signatory to both the CRC and the CRPD, the primary government intervention toward these goals is the care dependency grant (CDG). The CDG is an unconditional cash transfer available to low-income parents or primary caregivers of disabled children. When compared to other countries with similar histories and economies, this economic support to assist with the additional direct and indirect costs of disability is relatively strong and substantial. However, poor policy implementation, insufficient and uneven access and widespread systemic deprivation have limited progress toward CRC and CRPD commitments. Most disabled children in South Africa, especially those from economically poor families, have a lower quality of life than their non-disabled counterparts and much less access to critical health and educational services, worsened by high levels of social exclusion. The provision of social assistance cash transfers is important but insufficient for achieving the full spectrum of rights to which the disabled child is entitled. Similarly, this case study adds weight to the contention, well-documented by anthropologists of global health, that high-level human rights conventions represent positive intentions but are only the first step toward deeper change in signatory countries. Sustained change requires political will, coherent and decisive governance, budgetary allowances and monitoring and accountability mechanisms, which can only be realised at country-level. This presentation should be relevant to those interested in social protection and improving the disabled child's quality of life in the global south, as well as those working on similar programmes in the north, where austerity measures and economic crises threaten earlier progress.

From 'Retarded' Education to Authentic Life:^[SEP] A Personal Education Retrospective

Tammy Bachrach², Tim Woods ¹

¹ *Independent Researchers , Azusa, CA, United States*

² *Azusa Pacific University, AZUSA, United States*

This co-authored autoethnography will retrospectively explore the authors' experiences as children of parents with intellectual disabilities, a youth with an intellectual disability, and a non-disabled sibling living in the United States in the early days of special education law. This first-hand account discusses the author's educational experiences following the implementation of US Law; the Equal Education for all Handicapped Children Act (1975). The article reflects on the educational shifts within the US educational system within the last 45 years as well as the benefits and limitations of current special education practices which continue to rely on a deficit model of disability.

Relationships and the transition process from primary to secondary school: voices of adolescents with intellectual disabilities

Gemma Diaz Garolera, Maria Pallisera, Judit Fullana Noell

University of Girona, Girona, Spain

The Convention on the Rights of Persons with Disabilities commits all State Parties to guarantee that all people with disabilities receive the support needed for their social inclusion; while the Convention on the Rights of the Child commits them to ensure children's rights to meet with friends and join groups. Making choices and actively participate in community contexts allow children to develop in their daily basis, as well as building social networks that allow them to develop friendships and joining groups. Thirty people with intellectual disabilities (aged 17-45) participated in two research projects regarding their experiences in terms of relationships and social participation, focusing specifically on the barriers and supports encountered during their transition process from primary to secondary school. Data was collected through semi-structured interviews and focus groups, using visual methods such as drawing, charts and the photovoice method to help participants evoke their experiences. The analysis of the data collected illustrated that the relationships with their peers was one of the elements that came into play when assessing their pathways to secondary education. Specifically, the participants' narratives showed that many of them faced challenges when transitioning from primary to secondary school, including peer rejection, feeling different than others, loneliness and isolation, loss of friends or difficulties maintaining them, having to struggle a lot to overcome academic challenges, and a lack of relationship opportunities, among others. Therefore, to guarantee the rights of young people with disabilities in terms of friendship, some relevant practices should be considered, such as dynamics and practices that foster the development of peer relationships (mentors, buddies, peer support programmes), or the participation in extracurricular activities in the community, which offers opportunities to interact and grow together outside the school setting, among others.

11-05-2023

16:10 - 17:30 - Deafness III with International Sign Language - Gender, violence and accessibility Grand Hotel - Háteigur /

Deaf women in Norway – experiences and perceptions of accessibility at work.

Rannveig F. Sinkaberg, Svenja Hammer, Marianne Hedlund

Norwegian university of science and technology, Trondheim, Norwa

Deaf women in Norway – experiences and perceptions of accessibility at work.

This paper focuses on Norwegian deaf women's perspectives and experiences regarding work and their workplace, holding a human right perspective. This perspective ensures deaf persons' equality and non-discrimination in the work environment where sign language and modes of inclusion are factors as stated in article 27 in CRPD (United Nations, 2006). The CRPD committee (2019) has expressed concern about the development of working life in Norway with the persistence of discrimination based on disability particularly for women, including the denial of reasonable accommodation. Calling for more statistics and research regarding the situation of women with disability (United Nations Committee on the Rights of Persons with Disabilities, 2019), this study attempts to focus on deaf women working.

Based on a questionnaire that entailed questions about deaf women's work situation and their experiences of accommodations in working life as deaf, descriptive analyses were performed. The sample consists of N = 68 respondents between the age of 27 and 60. The participants were recruited through a Norwegian NGO and SoMe groups for deaf people.

First analyses show that 80% of the deaf women in the study work, 70 % work in the public sector and 74% have a higher education. The results on perceptions indicate that having a sign language interpreter improves the possibilities of having a job, work schedule flexibility and getting higher qualifications are perceived as important.

The results will be discussed in the frame of CRPD's understanding of work, accessibility, and women's rights to participate in working life without discrimination.

Masculinity in deaf entrepreneurship

Mette Sommer Lindsay,

Heriot-Watt University, Edinburgh, United Kingdom

Despite evidence of gendered aspects of disability, its relationship with gender in employment is scarce and disability is rarely mentioned in relation to gender and employment field (Mik-Meyer 2016). Disability studies and employment research "frequently conflates sex and socially constructed gender" (Sang et al 2016:569). This presentation aims to examine socially constructed gender in deaf business ownership through interviews and observations with nine deaf signing business owners (eight men and one woman).

This presentation is based on a PhD study in Denmark where several of the research participants are well-educated professionals running businesses with several employees and have high incomes. Thus, a solely negative perception of their path to entrepreneurship as being forced upon them by circumstance risks overlooking the positive motivations that may also be present and the individuals' privileges that might help explain their success.

This presentation presents the findings from this PhD study and focuses on a threefold aspect of how masculinity and deafness overlaps: firstly, deaf entrepreneurs' motivations in becoming entrepreneurs, secondly how business owners engage in networking in business contexts in Denmark (and build social and cultural capital), and thirdly how deaf business owners construct 'deaf ways' in their everyday contexts which might overlap with masculinity.

This presentation aims to expand the understanding of the field disabled (i.e. deaf) people in employment context, power, and oppression, both within the context of deaf related sector and general mainstream markets, by examining them through the lenses of Organisational Studies, Disability Studies and Deaf Studies.

Mik-Meyer 2016 "Gender and Disability: Feminizing Male Employees with Visible Impairments in Danish Work Organizations", *Gender, Work and Organization*, Vol. 22/2015 No. 6.

Sang, K.J.C., Richards, J. and Marks, A. (2016), "Gender and Disability in Male-Dominated Occupations: A Social Relational Model", *Gender, Work and Organization*, Vol. 23/2016 No. 6, pp. 566–581.

"I didn't ask for these messages!" - Digital sexual violence against D/deaf and hard-of-hearing teenagers: Prevalence, types and characteristics of the victims and perpetrators

Dennis Oberleiter¹, Katharina Urbann², Eva Hartmann¹, Malte Schott¹, Laura Avemarie¹

¹ *Ludwig-Maximilians-Universität München, Munich, Germany*

² *Humboldt-Universität zu Berlin, Berlin, Germany*

Background: D/deaf and hard of hearing (DHH) teenagers are at greater risk of sexual violence in the non-digital space (Kvam, 2004). Because they have a more communication-oriented media usage than their hearing peers (Hartmann et al., 2022, in press; Montiel, Carbonell & Pereda, 2016), DHH teenagers are exposed to the serious risk of experiencing digital sexual violence (DSV). As the first of its kind, this study surveys the prevalence and types of DSV against DHH teenagers in Germany. It, additionally, examines the characteristics of the victims and perpetrators.

Method: In a mixed-methods study, data are being collected from October 2022 to March 2023 at schools for the DHH. The sample consists of 200 DHH teenagers between 11 and 18 years of age. Media usage, exposure to seven forms of DSV, characteristics of the perpetrators, risk factors and protective strategies are being investigated through self-reported questionnaires and qualitative interviews. Class teachers reports on school prevention measures, data on participants' sociodemographic characteristics and psychological needs are also being collected.

Results: The data is currently being evaluated and final results will be presented at the NNDR research conference. Our pilot study (Hartmann et al., 2022, in press) showed that 82 % of the sample ($n = 16$) experienced at least one form of DSV. Unacceptable sexual questions (69 %) and facing non-consensual pornographic material (69 %) were reported the most. Questionnaire analysis indicated a greater risk of DSV associated with a young age, precarious situations, psychological needs, single-parenting, missing parental conversations, unattended media usage, online communication activity, number of followers and the number of own posts, comments, and similar.

Conclusions: Group specific help and prevention programs are necessary due to a high risk of DSV for DHH teenagers. Implications for future prevention programs will be discussed.

Young people's perspectives on hearing loss – when does a hearing loss become a significant hearing loss?

Eva Juul Toldam, Niels-Henrik Møller Hansen

CFD, 2860 Søborg, Denmark

Living with a hearing loss can be difficult. In this presentation we will display some of the major results from two qualitative studies of young people (age 13-30 years) living with a hearing loss (n=7) and deafblindness (n=7) in Denmark. The Deafblindness study has been done in cooperation with ISHD (Aalborg, Denmark).

The implications of hearing loss are experienced as temporal, and changing in regards to the context. Living with a hearing loss (and a vision loss) is fluid and demanding for young people navigating through adolescence. The presentation will be centered around two concepts, that enables an analytical approach to further our understanding of being young and living with a disability:

Young people as temporal *situational architects*

Solitude in dealing with disability

Behind the two concepts is the recognition of the changing of well-known categories such as deafness and types of hearing loss (as defined by the size of the audiological measurement of the hearing loss). They are challenged by advances in treatment (CI and Baha, hearing aids), the erosion of institutional arenas for people using sign language (e.g. schools for deaf people), and other societal development (e.g., individualism, acceleration). In this landscape of transition, we find it beneficial to broaden our understanding of hearing disability with the concept of *significant hearing loss* (based on the individual experience rather than external definitions).

The presentation will introduce empirical situations, where the hearing loss poses challenges for young people and thus become a significant hearing loss. Through the concepts of *situational architects* and *solitude* we will show how they try to master and change the situations, and thus take more control over the implications of living with a hearing loss.

11-05-2023

16:10 - 17:30 - **Rehabilitation, technology and accessibility I - Children and youth** Hilton Nordica - Meeting Room G /

Furuboda boarding school for young adults with disabilities: current projects and lessons learned

Elin Vinblad¹, Håkan Larsson²

¹ Furuboda School for People with Disabilities, Yngsjö, Sweden

² Furuboda Boarding School, Yngsjö, Sweden

Furuboda is a Swedish non-profit disability organization and a boarding school on a post-high school level for people with physical, intellectual, and acquired disabilities. Furuboda

was the first Swedish school for young adults with disabilities, and during our 60 years of working in the field, we have seen disability trends come and go on both educational, therapeutic, and political levels. Our team of speech and language pathologists, occupational and physical therapists, counselors, and rehab assistants reflect back on our current and previous work in both classroom- and therapeutic settings, during schooldays and at leisure-time, with the unifying concept of letting the students drive their own motivation forward by allowing them to take the leading role in their own lives. During our presentation, we will talk and use multimedia to present some of our current projects and missions.

Continued rehab for young adults with traumatic brain injury – how to apply a life-perspective to continued rehab and motivation after the most acute phase. For twelve years, Furuboda has been a stepping stone between hospitalization and the first steps back to the first stages of adulthood, which the students only saw a glimpse of or never entered before the accident. Focus: motivation, independence, cognitive- social- and language based training.

MISK – a music project to develop new solutions for students with severe physical disabilities, allowing them to create and perform music together with friends. Focus: independence, joy, empowerment, communication.

One ballot, one voice – a democracy centered project focused on increasing commitment and involvement in the previous Swedish election (2022) for young adults with disabilities. The participants explain how they have made sure to make their voices heard, and how they wish the electoral system would change in order to enable their partaking. Focus: democracy, human rights, empowerment, Bliss symbolics.

Personal growth through doing and participation, possible or not; experiences described by young adults with cerebral palsy

Lena Bergqvist¹, Ann-Marie Öhrvall², Marie Peny-Dahlstrand¹

¹ *Institute of Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Sweden*

² *Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Stockholm, Sweden*

Introduction: Performance of everyday activities and participation are often influenced throughout life in individuals with cerebral palsy (CP). However, it has rarely been described how persons with CP themselves perceive their performance of everyday activities. The aim of this study was to describe the experiences that young adults with CP, of less motor severity, have of performing activities in everyday life.

Participants and methods: Qualitative interview study with ten participants with CP, of less motor severity, aged 19-30 years. The data were analysed using a phenomenographic approach.

Results: The young adults with CP considered it extremely important to perform activities in everyday life. Performance of activities was described as what makes you develop as person. The participants expressed their hope of maintaining or developing their ability by

doing. They also pointed out the importance of feeling a sense of belonging through doing together with others in a social environment. Many situations involving performance of activities were characterised by the participants as demanding. The participants described how they felt diminished as human beings when activities proved too demanding and when they felt excluded. On the other hand, if their performance of everyday activities was facilitated and/or their social environment invited them to be involved in activities, this promoted participants' personal growth. Regardless of the outcome, participants paid a high price in terms of physical deterioration, pain, stress, mental and physical fatigue in their efforts to become who they wanted to be. Young adults with CP considered that, despite life being so demanding, it is important to perform everyday activities themselves, because *"when I do, I become someone"*.

Conclusion: Person-centredness and personally important activities should be used to meet the persons' wishes and needs in their efforts to grow through doing.

When love happens to you. Inclusive research about love and relationships.

Ásgeir Tómas Arnarson¹, Hekla Björk Hólmarsdóttir¹, Nína Margrét Ingimarsdóttir², Ragnar Smára³, Ágústa Björnsdóttir¹, Kristín Björnsdóttir¹

¹ *University of Iceland, Reykjavík, Iceland*

² , ,

³ *University of Iceland, Reykjavík, Iceland*

We will present findings from an inclusive research project which focuses on how disabled high school students understand and experience love and relationships. Inclusive research is a family of methods where non-disabled and disabled researchers work in collaboration instead of the more traditional hierarchical approach of professional researchers vs. research subjects. The research team includes three disabled university students, two non-disabled university researchers and one disabled university researcher. The research is on-going and started in autumn 2022. Four focus group interviews were carried out with 26 high school students and four semi structured individual interviews with two high school boys and two girls. The participants were aged 15 to 20 years old. Some had experienced love, but others had little or no experience of romantic relationships. All described the importance of love and relationships based on mutual respect and equality. Also, they believed that finding a partner would break barriers of social isolation and exclusion. They described the difference between friendship and love but claimed that it is impossible to understand the difference until love will happen to people. In the presentation we will describe the research process and describe how the young people who participated in this research were more open and willing to talk about the topic of love and relationship with other young people who also were disabled. Finally, we will claim that our findings are an important contribution to sexuality education for young people.

Bringing Disability Studies and Youth Studies Together to Understand Disabled Youth Transitions

Edmund Coleman-Fountain¹, Janice McLaughlin², Charlotte Pearson³, Tracy Shildrick², Nick Watson³

¹ *Northumbria University, Newcastle upon Tyne, United Kingdom*

² *Newcastle University, Newcastle upon Tyne, United Kingdom*

³ *Glasgow University, Glasgow, United Kingdom*

In disability studies youth transitions has been conceptualised as a linear process moving towards a pre-determined goal; with much of the focus on the transfer from child to adult services. In contrast youth studies, while not engaging with disability or disability studies, scrutinises the interplay between changing empirical contexts created by long term changes in labour markets and state approaches to welfare and the regulatory presence of societal norms about the 'right kind' of transitions and the 'right kind' of young adult citizens. This presentation makes the case for bringing youth studies and disability studies approaches together to generate a richer and more holistic understanding of disabled youth transitions. Bringing both bodies of work together can highlight how: (1) Material inequalities are still an important factor in disabled young people's lives and that difficulties during the transition period can be felt across adulthood. (2) Family is increasingly significant - and problematic - as a resource in disabled youth transitions as forms of state support dwindle. (3) Normative embodied markers of transitions influence judgements made about disabled young people making their way towards adulthood. (4) Transitions policy and thinking is flawed when it focuses on disabled young people having the right kind of aspirations to make the right kind of transitions. This collaboration can produce a relational understanding of transitional processes, situating disabled young people in the social worlds they are embedded in and moves away from a linear understanding of time. The presentation will conclude by introducing a new UK based Economic and Social Research Council comparative study of the inequalities and diversities of disabled youth transitions, which will draw from both disability studies and youth studies to provide a richer and more holistic understanding of contemporary disabled youth transitions.

Differences as potentials: Re-envisioning mobility and movements

Bhavnita Mistry, Donya Mosleh, Barbara Gibson

University of Toronto, Toronto, Canada

Movement and mobility in relation to disability are frequently discussed in terms of bodily deficits and/or disabling access barriers. Deficit-thinking separates people into categories of disabled or so-called 'able-bodied'. Either through medical treatments or rights advocacy, the goal inherent in these approaches is for disabled people to be as similar to non-disabled persons as possible, in order to have access to a normal/ized life. Normalization goals are problematic because they organize how disability and ability are understood and addressed in the contemporary world, perpetuating violent effects. To address this, disability scholars have increasingly called for alternatives to social narratives that position disabled people as outsiders-wanting-in to a pre-existing normative society. In this presentation we respond to this call by advancing an affirmative way of thinking about disability and differences. To demonstrate these ideas, we will present a short video developed in a recent Canadian study exploring movement potentials with five disabled young people. Through their stories we consider the multitude of ways in which creative mobilities can enable human flourishing, while attending to the socio-material forces that constrain such efforts. In celebrating diversity as fundamental to the human condition, we argue that bodily differences can be understood as forces of positive change rather than deficits.

11-05-2023

16:10 - 17:30 - **Services I - Professionals' perspectives and methods**
Grand Hotel - Huginn /

"Faith comes and removes all questions": The Encounter of Faith, Social Workers, and Ultra-Orthodox Parents of Children with Intellectual -Developmental Disabilities

Anat Freund¹, Amit Zriker², Reizy Erlich¹, Yshay Shuker¹

¹ *University of Haifa, Haifa, Israel*

² *Ruppin Academic Center, Emek Hefer, Israel*

Background and Purpose. The collectivist way of life of the ultra-Orthodox society highlights the process of caring for family members with intellectual-developmental disabilities. Hence, the importance of understanding the perceptions and attitudes of those involved in the caring process in order to optimally adjust the services for the benefit of children with intellectual-developmental disability and their families. Another important goal is to promote a culturally-sensitive social policy in this field.

Methods. Data collection was carried out through semi-structured interviews held with 15 family units that included parents and a social worker who serves as the family's case manager. The inclusion criteria was having a child (under 18) with intellectual-developmental disability. The main research question was as follows: *What is the meaning of caring for a family member with intellectual-developmental disabilities in the ultra-Orthodox society?* A qualitative-phenomenological research method was chosen to examine the lived experience of the factors involved in the phenomenon under study.

Results: Three main themes were found in all three groups. The first was **Relationship with the nuclear and extended family**. This theme dealt with family ties and the social support of the nuclear and extended family. The second theme was **Relationship with the community**. This theme focused on community ties, such as formal and informal assistance in the ultra-Orthodox society. The third theme was **Religion and belief**. This theme highlighted issues of faith, religion, and belief.

Conclusions and Implications: The issue of caring for people with intellectual-developmental disabilities in the context of a faith-based society has been partially investigated. With the rise in awareness of the need for professional and formal care for these individuals, it is of great importance to better understand this phenomenon and develop a tailored policy that will include culturally-sensitive interventions.

Interprofessional collaboration for children with physical disabilities: a scoping review

Line Myrdal Styczen¹, Sølvi Helseth¹, Karen Synne Groven¹, Mona-Iren Hauge², Tone Dahl-Michelsen¹

¹ *Oslo Metropolitan University, Oslo, Norway*

² *VID Specialized University, Oslo, Norway*

Objective: Children with physical disabilities receive a variety of child- and family-directed services and often the children must relate to several different professional contacts. Vice versa the health, social care and education professionals, providing the services must relate to the child in question, the family in question and the other service providers. Thus, *interprofessional collaboration* is vital in the context of service delivery for children with physical disabilities. The aim of the current study is to explore the research status on interprofessional collaboration for children with physical disabilities seen from the point of view of the actors involved.

Method: A scoping review methodology is chosen, as a scoping review allows for a comprehensive mapping of the available research. The steps of this scoping review involve identifying a research question and developing a protocol, identifying relevant research, study selection, charting the data, summarizing - and analysing the data, and reporting and discussing the results.

Results: Identified records through database searching after duplicates removed were 3875, plus 6 from hand searches. 27 references were included in the scoping review. Our results reveal how the research concerning interprofessional collaboration for children with physical disabilities seen from the point of view of the actors involved evolves around internal – and external interprofessionalism. Internal interprofessionalism relates to aspects that is situated within the context of individuals. External interprofessionalism is related to aspects that are situated to the arenas surrounding the individual. Four features display as significant: role, interaction, culture and competence, they are all considered both promoters and barriers for internal- and external interprofessionalism.

Conclusion: Our results indicate that that internal - and external interprofessionalism do not operate in isolation. Interprofessional collaborations for children with physical disabilities are revealed to be complex, but also dynamic, and involving several facilitating and hindering features.

Social challenges of hearing loss: Professional knowledge and practice

Inge Kryger Pedersen,

University of Copenhagen, DK-1014 Copenhagen K, Denmark

Hearing technology is a major scientific breakthrough as it restores hearing for deafened and hearing-impaired people around the globe. However, social scientific research finds communicative problems in group relations, thus generating social exclusion and loss of energy for people with hearing loss. This paper's thesis is that the current professional field is characterised by a knowledge gap between individualized treatment and the ongoing social implications of hearing loss and usage of hearing technologies in everyday life situations.

The paper investigates professionals' discretions (diagnosis, inference, and treatment) when handling clients' social challenges in balancing hearing loss and school (children and young

people) or working life (adults) in the context of Danish society. In Denmark, it is estimated that about a seventh, i.e. 800,000 citizens of the whole population suffer from hearing loss. Recent social surveys indicate social isolation, communicative and emotional difficulties for users of cochlear implants and other hearing technologies. Crowded and noisy situations as well as bad acoustic spaces may lead to high mental and emotional energy usage and communicative constraints on social participation.

Drawing on survey findings and documents as background material, and in-depth qualitative interviews with a broad spectrum of different kinds of professionals within the field of hearing impairment, this paper demonstrates how professionals understand and work with issues of social inclusion for people with hearing loss – or not. The findings are discussed to synthesizing multidisciplinary expert knowledge about people with hearing loss. The paper concludes by comparing professional knowledge forms and procedures concerning social inclusion with the possible tension between individual strategies and activities in social domains of school, education and work.

Exploring staff's use of power against residents with intellectual disability through floor plan drawings

Stine Marlen Henriksen,

Nord University , Stjørdal, Norway

A common goal across countries and care services to people with intellectual disabilities is to prevent unnecessary and unwarranted use of power. However, service providers can be unaware of the many ways in which power can be used, and researchers can have difficulties identifying subtle forms of use of power. To address this there is a need for creative methods enabling researchers to discover and analyse multiple and complex forms of use of power. This paper illustrates one such method; construction and analysis of floor plan drawings. Drawing on data from an ethnographic study of everyday life in a Norwegian group home for people with intellectual disabilities, this paper shows how use of floor plan drawings of the group home resulted in a more comprehensive understanding of the staff's use of power against residents. Among other things, this sociomaterial approach lead to increased understanding of the physical surroundings impact on staff's use of power, increased awareness of the subtle forms of use of power and of its total extent in the residents' everyday lives.

11-05-2023

16:10 - 17:30 - **People with ID ÖBÍ 1 Sigtún 42 /**

What has the Covid-19 pandemic meant for people with Profound and Multiple Learning Disabilities in the UK?

Jill Bradshaw¹, Sue Caton², Samantha Flynn³, Amanda Gillooly⁴, Richard Hastings³, Chris Hatton², Andrew Jahoda⁴, Roseann Maguire⁴, Anna Marriott⁵, Peter Mulhall⁶, Edward Oloidi⁷

¹ *University of Kent, Canterbury, United Kingdom*

² *Manchester Metropolitan University, Manchester, United Kingdom*

³ *Warwick University, Coventry, United Kingdom*

⁴ *University of Glasgow, Glasgow, United Kingdom*

⁵ *National Development Team for Inclusion, Bath, United Kingdom*

⁶ *Ulster University, Ulster, United Kingdom*

⁷ *University of South Wales, Cardiff, United Kingdom*

The Coronavirus and People with Learning Disabilities (intellectual disabilities) Study is a UK-wide Study that has been tracking the experiences of people with intellectual disabilities during the Covid-19 pandemic. Family carers/paid support staff of adults with PMLD were invited to take part in three surveys over 12-months. Family carers had input in to the survey design and the interpretation of the results. This presentation explores the experiences of people with PMLD in the UK, as reported by carers of adults and suggests what we might do differently to support this group in future.

Most people (60%) with PMLD lived with family. Over a fifth of people were shielding in the final wave of data collection. Over half (56%) of people with PMLD were getting less support now than before the pandemic with around half of these having been informed about these changes. Most people with PMLD (63%) had NOT been doing service-supported community activities in the last four weeks before the survey. Nearly half of people with PMLD were reported to be paying for services that they were not receiving. Carers reported that their health and wellbeing had been affected.

Life during the pandemic has been particularly difficult for people with PMLD and their carers. When asked what would be needed to make a future lockdown easier, the most common responses were support to keep active (64%), support to keep busy (53%) and knowing support workers were vaccinated (53%). Ways of supporting people to active and busy are explored, including the need for equipment and ways of supporting participation online.

Persons with ID's perception of their social services in Sweden during the COVID-19 pandemic

Lisa Palmqvist¹, Kristin Alfredsson Ågren², Käckér Pia², Lidström Helene²,
Danielsson Henrik²

¹ *Gothenburg University, Gothenburg, Sweden*

² *Linköping University, Linköping, Sweden*

The Covid-19 pandemic had major consequences for persons with intellectual disability (ID) who receive social services under the Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS) in Sweden. Reasons for this, among other things, are that many municipalities periodically closed Daily activity services during the pandemic, and restrictions on visitors was introduced in group homes with services, and service housing with special service. No complete lock down took place in Sweden as in many other countries. Schools stayed opened and people were aloud outside. Nevertheless, for an adult

with ID, much of everyday life is centered around their Daily activity center and their home. Thus, it can be assumed that the effects for persons with ID were substantial.

However, it is unclear how persons with ID perceived in what way their service was affected during the pandemic and what consequences this had on their everyday life. Therefore, the aim of the study was to examine how persons with ID feel regarding satisfaction with social care services, involvement, and participation due to the restrictions implemented during the COVID-19 pandemic. The study has a qualitative design where a total of 5 focus groups with persons with ID were carried out, (n=24).

Preliminary results show that although many persons with ID experienced fear and worry during the pandemic, the extent of the consequences was different depending on how the Daily activity services, group homes, and service housing implemented alternative activities and digital solutions. By giving insight to the consequences of the restrictions used during the Covid-19 pandemic, the results from this study will support policy makers and social service providers in their preparation for future crises. During the presentation results and implications of the results from the study will be presented and discussed.

Living through times of crisis: How has COVID-19 pandemic affected persons with intellectual disabilities in supported and service housing?

Sonja Miettinen,

Finnish Association on Intellectual and Developmental Disabilities, Espoo, Finland

On the 11th of March 2020 WHO declared a pandemic due a novel virus causing acute and severe respiratory illness. The virus was identified as a type of a coronavirus and the illness it caused was named as COVID-19. Countries worldwide have taken measures to protect their citizens from the disease and control the pandemic, including closure of public places and social distancing measures. However, these measures have been acknowledged to often have adverse social impacts, which seem to pile on those who already are in a more vulnerable position in the society.

This presentation explores the experiences that people with intellectual disabilities (ID) have of the COVID-19 pandemic and the ways it was managed in Finland. The presentation is based on a study that involved in-depth interviews with adults with ID who use housing services, their family members and support workers. The aim was to find out what the interviewees tell about how the everyday life of residents with ID changed during the public health crisis and how these changes affected their basic capabilities.

The presentation involves a brief description of the strategy Finland adopted in managing the COVID-19 pandemic, followed by the results of preliminary analysis of the interview material. The results indicate that while governmental guidelines emphasised protecting basic human rights of people with disabilities while managing the epidemic, this has not always been the case on the grass-roots level. Persons with ID have often experienced limitations in their capabilities for social contact, rewarding activities, and self-determination due to local responses to the epidemic. The results highlight fragility of the citizenship status of persons with ID and call for measures to prevent permanent loss of important capabilities.

With the best intentions

Line Melbøe, Aina K. Kane

UiT The Arctic University of Norway, HARSTAD, Norway

According to article 12 of the Convention on the Rights of Persons with Disabilities everyone has the right to make decisions about their own life, independent of cognitive ability. Each person has the right to be equal before the law, without any form of discrimination (UN Declaration of Human Rights, article 7). Yet, people with intellectual disabilities have a long history of examples where their human rights, and especially their autonomy, have been put in jeopardy. Extraordinarily challenging times, such as the Covid-19 pandemic, seem to increase the risk of limiting the rights of people with intellectual disabilities. However, so far there is scant empirical research about the self-determination of people with intellectual disabilities during the pandemic.

The background for this presentation is the qualitative research project “Independent living and infection control – experiences with provision of home-based services for adults with intellectual disabilities under Corona measures”. Based on interviews with 19 service providers in June 2020 about their experiences with safeguarding infection control and independent everyday life for persons with intellectual disabilities during the first Corona lockdown in the spring of 2020, we aim to identify and discuss implications of the pandemic on the right to self-determination for people with intellectual disabilities in Norway. We particularly aim to shed light on how relevant information was made accessible for persons, how infection control measures were implemented, and on which grounds and intentions those measures were implemented.

11-05-2023

16:10 - 17:30 - Work and employment I - Crafting creative connections. Constructing collaborative interdisciplinary space for the advancement of disabled people and work Hilton Nordica meeting room I /

- Moderator: Jannine Williams, QUT

Thinking outside the (activation) box? Advancing workplace inclusion for people with mental health conditions

Emilie Rosenstein,

University of Applied Sciences and Arts Western Switzerland , Siege, Switzerland

Since the 1980s, activation is major driving force in the (re)definition and shaping of contemporary social policies, including disability policies. However, recent literature has shown that it builds on return-to-work paths that are not equally accessible to disabled people, thus resulting in both higher selectivity (Rosenstein & Bonvin, 2020) and non-take-up (Rosenstein, 2021) that may arise from a broad range of ableist norms at the heart of active labour market policies (Scholz & Ingold, 2021; Piecek et al., 2017).

This contribution is the starting point of a new research project, with a twofold focus on innovative practices in the prevention of psychosocial risks at work on the one hand, and in the development of return-to-work schemes and tools specially dedicated to people with mental health conditions on the other hand. In this perspective, we will firstly present the limits of active labour market policies deployed by the Swiss welfare state for the recipients of Disability insurance benefits with mental health conditions, based on a longitudinal mixed methods research design. Secondly, we will present the main findings of an exploratory review of the literature. The aim is to identify and discuss innovative practices in both preventing psychosocial risks and promoting return-to-work schemes for people with mental health conditions, in order to point out the potential of non-ableist approaches in advancing workplace inclusion and to reflect on their implementation in the Swiss context.

Part of the results presented is drawn from a research project carried out in the framework of the National Centre of Competencies in Research “*LIVES – Overcoming Vulnerability: Life Course Perspectives*” (Swiss National Science Foundation, 2011-22).

Safe spaces in ableist workplaces

Frederike Scholz ¹, Amber Kersten², Manon Krabbenborg², Marianne Van Woerkom², Joanna Szulc ³

¹ *Tilburg University, Tilburg, Netherlands*

² *Tilburg University, Tilburg, Netherlands*

³ *Gdansk University of Technology, Gdansk, Poland*

While there are formal adjustments that are made to include neurodivergent people at work focusing on the physical space, employers ignore that successful implementation also requires informal adjustments that employees themselves might have to make of the mental space themselves, in the form of “safe space crafting” to be able to undertake productive work. There is growing literature from the perspective of employers or line managers on how to make the workplace more inclusive for neurodivergent people by providing physical

adaptations, but the data on individual employees and their experiences of creating a safe mental space is still scarce. The aim of this project is to create a model demonstrating adaptations to the physical space, but predominantly to the mental space from the perspective of neurodivergent employees to show that accommodations can have different outcomes. The longitudinal study employs semi-structured interviews with employees and their employers over a period of one year.

Challenging the norms of ableist research: A roadmap for more inclusive research with neurominorities.

Joanna Szulc ¹, Michal Tomczak¹, Frederike Scholz ²

¹ *Gdansk University of Technology, Gdansk, Poland*

² *Tilburg University, Tilburg, Netherlands*

Neurodivergent individuals make up 20% of population. Whilst the concept of neurodiversity suggests that all humans vary in terms of our neurocognitive ability, the terms such as neurominority, neurodivergent, or neuroatypical are umbrella terms for the subset of neurodivergent conditions, such as attention deficit hyperactivity disorder, autism, dyspraxia, or dyslexia which imply that one's cognitive profile is not "typical". Despite their unique strengths that make them excel as professionals, neurodivergent individuals are often barred from work opportunities and experience employment exclusion. That is why the community of neurodivergent employees has been subject to increased research attention among Management scholars aiming to explore the topic of inclusive employment and decent work. However, from the point of view of research design, research with neurominorities can bring certain challenges. For instance, neurotypical researchers may experience difficulties in understanding concerns or specific experiences of neuroatypical participants, which could then lead to a lack of appreciation of what research participants might find difficult in the process or how they interpret what researchers are doing. In the light of only limited advice about how research with neurominorities should be conducted in an inclusive way, we offer an integration of the fragmented literature on this topic and combine it with our reflexive notes summarizing our own research experiences as neurotypicals who conduct research with neurominorities. We eventually arrive at a roadmap to aid neurodiversity researchers in reflecting on and adjusting their research design choices to be more neurodiversity-inclusive. We focus on the practical issues in recruiting participants, the practice of conducting research, and suggest avenues for further methodological development. In doing so we encourage researchers to think pre-emptively about the issues specific to research involving the neuroatypical community to ultimately increase involvement and collaboration as well as the quality of the research processes and their outcomes.

A disability and gender analysis of the Australian Twittersphere. Social responses to 'Australian of the Year'

Jannine Williams, Maria Khan, Alice Miller

QUT, Brisbane, Australia

Media play an important role in the social construction of leadership. More recently social media emerged as a medium for leadership, not only in terms of social discourses about leaders and leadership, but also leaders' use of social media. Twitter has emerged as a key

platform for social commentary shaping public discourse about incidents, individuals and public figures.

The Australian of the Year award is made to citizens who are recognised as inspiring individuals and leaders at community, State or Territory and national levels. As such recipients receive significant media attention and public sharing of opinions and resources connected to the recipients and their activities as award incumbents.

Working with a longitudinal collection of tweets from accounts that are identified as Australian, this study explores social responses to the recipient of the 'Australian of the Year' award over a five year period. The findings will explicate how public sentiment and discourse on leadership can be influenced by hashtag campaigns, trends, influential tweets and conversations in popular social media.

The paper will reflect on the methodological possibilities and opportunities afforded by longitudinal social media data and the insights gained from quantitative and qualitative analysis.

Multi-modal Diaries and Allyship: Inclusive Method Design for Capturing Experiences of Disabled People at Work

Anica Zeyen ¹, Onana Branzei ²

¹ *Royal Holloway School of Business and Management, London, United Kingdom*

² *Western University, Ontario, Canada*

Current research calls for a better understanding of the working lives of disabled people. Such research is of particular relevance given the low employment figures for disabled people. Furthermore, there is an increasing call to develop methods and methodologies which progress inclusive and collaborative approaches, that has the voices and experiences of disabled people at its core and create positive impact on disabled people's work lives.

We respond to this call with a research method developed to capture the experiences of disabled people at work during the Covid-19 pandemic. We followed 24 disabled workers living in the United Kingdom over a 22-months period through a diary study which included in-take, multiple follow-up and exit interviews. We introduced multiple innovations into our study design to make it inclusive and co-created. First, disabled people in our study were co-ethnographers rather than participants. This shift gave our co-ethnographers control of their own stories by deciding the frequency, reasons for and content of their diary entries. Second, to accommodate the diverse range of disabilities within our sample, we did not employ a specific form of diary; rather our co-ethnographers chose the modality. Our data includes hand-written and typed diaries, photos, drawings, poems and one-line email subject lines. Third, to ensure appropriate representation of insights, we engaged our co-ethnographers in follow-up interviews to reflect with them as well as to discuss themes with them – both within their journeys and across all. Fourth, we employed an allyship approach to data analysis, i.e., in our two-person research team, one is disabled and one is not, giving as both an insider and outsider view which enabled us to uncover themes that we would individually have not. In addition to the main study, we have conducted versions of this study with disabled people in Uganda and South Africa.

Friday, May 12

08:30 - 09:30 - **Keynote address by Ingela Holmström with International Sign Language followed by Panel discussion** Grand Hotel - Gullteigur A/B /

09:55 - 11:15 - **Disability and the lifecourse II - Transition to adulthood** Hilton Nordica meeting room H /

Students with Special Needs Developing Social Roles at a Specially Planned Youth Education School in Denmark

Cecilie K. Moesby-Jensen¹, Inge Storgaard Bonfils²

¹ *Absalon University College, Roskilde, Denmark*

² *Copenhagen University College, Frederiksberg, Denmark*

This paper examines how special needs education (SPYES) targeted at young people with ID contributes to their identity development and social roles. The research was designed as a single case study (Yin 2003) and involved ethnographic fieldwork and interview with eight key informants: Two experienced teachers; two managers and four students, between 16 and 24 years old. The study was informed by sociological theories in the intersection between disability research (Wolfensberger, 2011), learning theory (Wenger 1998) and the theory of recognition (Honneth 2006).

The analysis showed how SPYES supports the development of students' participation at the school and how the enhancement of the students' social participation takes place both in the school setting and settings outside the school. This is done by shaping opportunities through a trusting and understanding relationship between the teachers and the students as well as through supportive friendships with peers. Further, opportunities are shaped by supporting the students' potential to have an active leisure life, and experience work-life through internship, voluntary work and participation in the school's workshop.

This study contributes to the understanding of the role of special education facilities in developing young people's identities, social roles, participation, and self-determination in their transition to adulthood. A strong commitment to social participation, recognition, and equalisation of opportunities for young people with ID, seems to be an enabling factor in shaping a social environment for learning and the development of a positive identity and valued social roles. The study also points to how the special educators' relational competencies were essential for the development of this learning environment, which is in line with previous research in the field (Aspelin et al. 2020). The findings suggest that the provision of these special education facilities is essential in providing opportunities for young people with ID to participate in society.

Disentangling the Educational Pathways and Work Outcomes for Disabled Young People in England

Angharad Butler-Rees, Chatzitheochari Stella,

University of Warwick, Coventry, United Kingdom

Disabled children and young people are more likely to lag behind in educational and occupational attainment in adulthood. Despite enduring sociological interest in the impact of social class on educational experiences and outcomes, the influence of disability has largely been overlooked. To a certain extent, this can be attributed to medical understandings of disability that view negative educational outcomes as natural consequences of long-term conditions and impairments, disregarding the influence of social factors including stigma and systems of power and oppression in (re)producing disadvantage. 'Educational Pathways and Work Outcomes of Disabled Young People in England' is a qualitative, longitudinal study that seeks to rectify this omission by exploring disabled young people's experiences in English mainstream schools, and the consequent effect on educational and occupational trajectories. The study consists of two waves of semi-structured interviews with 35 disabled young people (aged 15-17) from across three disability groups: autism, dyslexia and physical disabilities. These interviews enable us to explore young people's experiences of education along with the various barriers they may encounter in their educational journeys. An intersectional approach is also taken, interviewing young people from across different social class backgrounds to explore how disability and social class may coalesce in framing young people's educational experiences. This presentation will draw together initial findings from across the two waves of data collection, offering insights into the role of various social mechanisms, including that of stigma, in perpetuating socio-economic disadvantage amongst disabled young people.

Changes in disability policies: young adults with intellectual and their families navigating opportunities for adulthood.

Tomas Puentes Leon,

University of Leeds, Leeds, United Kingdom

In the last decades, disability policies in Chile have shifted from considering disability as an individual problem to its recognition under a rights approach (Cisternas Reyes, 2005), with the ratification of the CRPD in 2008 leading to a new legal framework which has promoted inclusion and anti-discrimination laws.

Despite the increase on social programmes seeking to enhance participation of persons with disabilities in society, its mean-tested approach has meant that, for most of them, welfare has still being provided mainly by their families. School inclusion programmes and mandatory quotas for hiring people with disabilities have been policies that sought to equate conditions for known areas where difficulties are most seen, however, within disability, intellectual disability have tended to present additional layers of barriers for them to perceive some their improvements.

Families, then, who are also carrying their own tensions derived from overprotection practices (Callus et al., 2019) have to navigate on how to promote participation of their members in mainstream activities. Additionally, within a context of limited opportunities, work

tends to be considered as a constituting aspect between adults, but less than half of persons with disabilities have been included in the labour market (SENADIS, 2015).

This presentation focuses on some of the difficulties commented on the transition from the educational system to work, drawn from interviews with young adults with intellectual disability and their families on their dialogues around adulthood. Families are constantly dealing with an ambivalent position of enabling and constricting opportunities, where the lack of support or bad experiences in the past, such as truncated educational journeys, have influenced the imagined possibilities for the future of young adults with intellectual disability.

Tracking transition pathways of young persons with intellectual and developmental disabilities

Jan Šiška¹, Šárka Káňová², Marie Černíková³, Tereza Havráňková³, Kateřina Horská³, Kateřina Wiesnerová³

¹ *University of West Bohemia and Charles University, Pilsen, Czech Republic*

² *University of West Bohemia , Pilsen, Czech Republic*

³ *University of West Bohemia , Pilsen , Czech Republic*

A substantial research evidence suggests that transition of young persons with intellectual disabilities adulthood is not linear. However, little known about what constitutes successful transition. This study aims to respond to the gaps in the knowledge base related to the lived experiences of young women and men with intellectual and developmental disabilities as they transition from school to adult life. The overarching aim of the PEDAL study is to understand what is needed to ensure they experience good quality of life outcomes as active citizens. This primarily qualitative project uses innovative research methodologies to explore the experiences, barriers and facilitators for successful transition to adulthood from the perspective of a number of stakeholders but with a particular focus on young people themselves. Preliminary findings indicates cross-sectional co-operation as one of the key predictors of successful transition. In contrary, absence of multidisciplinary support often forces young people with IDD and their families to retain in formal education and on segregated pathways with limited opportunities to learn from and to engage with new experience in other domains of life relevant to active citizens.

12-05-2023

09:55 - 11:15 - **Policy and theoretical perspectives IV - Diverse approaches in disability studies** Grand Hotel - Gullteigur A /

Persons with Disabilities and a 'Dignified life'

Hanna-Maria Niemi,

University of Eastern Finland, Joensuu, Finland

This presentation combines philosophical and human rights perspectives to the study of disability. The basic question in the presentation is, how can we move from the theoretical premise that simply being human is enough to have dignity to the practical conception that certain rights are needed to secure a dignified life. The role of human dignity in the human rights system seems to hold both beliefs.

This presentation adopts the premise that being human without further qualifications is sufficient for having dignity. The focus of the presentation is on analyzing, how this dignity is then protected: even though dignity is not based on any qualifications, but simply on the ethically fundamental fact of being human, the (legal) practice needs to give more concrete content to dignity and determine what belongs to a dignified human life. In other words, in order to have any relevance the abstract commitment to human dignity must be concretized. Persons with most severe disabilities challenge our attempts to give concrete substance for our conception of dignity. They typically have obstacles in articulating their wishes about their life plans and have physical or mental restrictions for action. But we still recognize their right to live a 'dignified life'. Hence, it becomes understandable why dignity is often linked with 'typical human life' with its various basic attributes or capabilities. The presentation analyses the concretizations that can be given to human dignity. The focus is on the different types of norms that can follow, basically prohibitions and ideals. The analysis utilizes Lon Fuller's idea of law, in general, as exemplifying two different types of morality: morality of duty and morality of aspiration. The aim is to elaborate the nature of the concretizations and the idea of typical human life connected to those.

Relational and extended selves: blurring the boundaries between ability and disability

Maija Aalto-Heinilä,

University of Eastern Finland, Kuopio, Finland

In Western philosophical tradition human beings have typically been conceived as atomistic entities whose cognitive and moral abilities are internal to themselves. For example, the Cartesian thinking subject is taken to be able to gain knowledge despite abstracting himself away from other people and from his physical embodiment and surroundings; and the subject in classical liberal thinking is an independent, self-determining agent who can choose and implement his own plan of life.

Nowadays this atomistic conception of human beings and the internalist conception of the human mind has been questioned. Especially feminist philosophers have argued for a *relational* conception of selfhood, in which the self is seen as constituted in and through relationships with others. Likewise in epistemology, feminists have emphasized the social construction of knowledge and the dependency of a person's epistemic abilities on the available epistemic resources. In philosophy of mind, it has been acknowledged that the human mind is in many ways extended and embedded into its surroundings and is not located solely in a person's brain.

These new ways of understanding selfhood and the mind open up new possibilities for thinking about the ability/disability distinction. For example, if *all* humans are seen as constituted by and dependent on their web of relations, then the concept of autonomy must

be understood so that it is compatible with this dependency. This makes it possible to extend the concept of autonomy to persons who previously were thought to be incapable of it. Likewise, if epistemic and cognitive abilities are not solely internal to each person, a lot can be done to either enhance or to obstruct those abilities. The aim of my presentation is to discuss the implications for the ability/disability divide if we see humans as relational beings whose minds are extended and embedded.

Rethinking the body in a human rights perspective

Lisa Pfahl, Rouven Seebo,

Universität Innsbruck, Innsbruck, Austria

In addition to the knowledge of symbolic orders, bodily experiences remain important for the formation of agency and social movements. However, many theories of the body fail to address the social dynamics of disability because they disregard the potential of disabled bodies as drivers of social development. Their starting point is a normalized body. But how can experiences of disability be brought into theories of the body?

In this contribution, criteria for a non-ableist theory of the body will be developed. Phenomenological approaches explore the body as a site of attention, awareness, pleasure, anguish and pain; they can be used to ask how disabled bodies feel from the perspective of the experiencing subject. Most approaches in the social sciences deal with disabled bodies from the outside, i.e. their representative and performative effect. Disability studies differentiate between disability and impairment and argue for a mutual constitution of the felt body and the visible body. To reconstruct disabled bodies as historical, social and experiential objects, we draw on anthropological and sociological approaches to understand when a body becomes a subject.

Drawing from Gesa Lindemann's social theory (2018), we consider subjects as bodies extended in space, which are symbolically charged as well as socially, legally, politically determined through contingent orders. Reading the CRPD which conceptualises disabled persons as diverse entities open to development and violation, and addresses equality as well as the particularity of bodies, the paper will outline an understanding of the body based on the human rights perspective, drawing together both sociological and phenomenological approaches. The right to dignity and freedom of subjects take centre stage in this conception. Building on these considerations, we will ask: Can different experiences and assumptions about the body change social dynamics?

Reference:

Lindemann, Gesa (2018) *Strukturnotwendige Kritik. Theorie der modernen Gesellschaft* Bd.1. Weilerswist: Velbrück

(De)Constructing Networks of Exclusion: Theorizing Disability through the Arts

Ryan Weber,

Geisinger Commonwealth School of Medicine, Scranton, United States

The body is an aesthetic object. As such, it is the site of overlapping and often competing discourses that are woven into a dense web of contingent values—forces that shape how societies diagnose, treat, and “cure.” Yet the people and institutions tasked with carrying out these goals are necessarily situated on shifting platforms, which often yield an uneven distribution of time and resources. The foundations of these imbalances can be traced back to the 19th century. It was during this period that the arts and medicine found an opportunistic union as they contributed to the circulation of the mutually reinforcing narratives of progress and degeneration. In literature, scholars have long noted this concurrent agenda. However, in music, relatively few studies have focused on the way critics have blurred the lines between biological and aesthetic concepts of health.

Therefore, taking up Lennard Davis’s call to examine how “society, narrative, and politics work to oppress bodies of difference,” this paper will analyze writings by music critics, medical practitioners, and social theorists. By placing their work into counterpoint, I will reveal the mechanisms by which aesthetic, biological, and moral concerns were conflated in a mutually reinforcing matrix of aesthetic normativity that resulted in new networks of exclusion. My methodology entails a four-part analytical framework to deconstruct their arguments: labeling, grouping, evaluating, and containing/controlling. Thus, by bringing the body back into the discourse of aesthetics, this paper will problematize disciplinary boundaries, shed light on the appraisal of disability in the 19th and 20th centuries, and offer renewed attention to the power of rhetoric to normalize the nation in the contemporary world.

12-05-2023

09:55 - 11:15 - **Human rights II - Structural and Intimate Violence Against Women with Disabilities** Grand Hotel - Hvammur /

- Moderator: Tommie Forslund, Stockholm University

System abuse, systemic violence and structural violence

Hanna Björg Sigurjónsdóttir¹, Jim Rice²

¹ *University of Iceland, Reykjavík, Iceland*

² , ,

In the 1990s, Tim and Wendy Booth detailed the numerous ways in which parents with intellectual disabilities had to contend with practices and policies that cause harm, rather than provide support. The Booths articulated these as forms of 'system abuse.' Due to the depth and range of the issues they explored, it would seem that there is little more to say. However, we contend that this work needs to continue. First, the forms of system abuse discussed by the Booth in the 1990s are still extant. Due to, arguably, poor institutional memory in child and family welfare systems, workers continue to practice these forms of abuse and as such there is a need for researchers and activists to conduct research and raise awareness in this area. Secondly developments in the larger society have opened up new spaces for surveillance and abusive practices which warrant attention. Lastly, the concept of system abuse could also be elaborated as systemic or structural violence. While synonymous in certain regards, the utility of the framework of violence will be considered

Reproductive Coercion and Violence Towards Women with Disabilities: A Scoping Review

Coralie Mercerat¹, Laura Pacheco², Marjorie Aunos², Marie-Marthe Cousineau²,
Ami Goulden²

¹ *TELUQ University, Quebec, Canada*

² , , *Canada*

Women with disabilities are subject to multiple and intersecting forms of violence, including reproductive violence, a form of violence that disregards human rights and has multiple and pervasive impacts on social, emotional, and physical health. Despite recognizing the issues and rights of women with disability within their reproductive journey, there is scant literature.

This presentation aims to share the results of a scoping review investigating and synthesizing the research literature related to reproductive violence against women with disabilities within Canadian and international contexts. Within a disability justice framework, this scoping review considers the root causes (including systemic violence perpetrated against women with disabilities) and intersecting levels of oppression, including classism, racism, sexism, heterosexism among others. The commitment to community participatory approaches and engagement with women with disabilities is particularly important within this project, and these approaches will be described in the presentation. The research team (researchers-three of which are disabled women-, two student researchers and two women from the community) used Arksey & O'Malley's framework and met at different phases in the process to reach an agreement of texts selected based on the inclusion and exclusion criteria. Five themes identified in this review were: 1) concepts defining reproductive violence; 2) places where such violence is perpetrated; 3) actors playing a role in this violence; 4) strategies used by women with disabilities to overcome violence; 5) legal and official actions adopted to counter this violence.

The findings have several implications. First, they will be used to forge collaborative community-based knowledge mobilization initiatives- sharing and reflecting on research results with women with disabilities and key stakeholders. Second, they will support the development of an action-oriented research program based on the knowledge synthesis, experiential knowledge, and participatory community-based research principles.

Exploring intimate partner violence of mothers with intellectual disability within child welfare court reports in Atlantic Canada

Laura Pacheco¹, Marjorie Aunos²

¹ *Memorial University, St-John's, Canada*

² , ,

Violence towards women with disabilities is a significant social issue that requires urgent multi-systemic attention and intervention. Many mothers with intellectual disability (ID) experiencing intimate partner violence (IPV) are also subject to disproportionate rates of child welfare intervention. Despite this structural disadvantage, there is a dearth of research that explores and describes intimate partner violence in the lives of mothers with ID in receipt of child welfare intervention. Using a feminist disability lens, this study employs critical content analysis to explore the child welfare court reports of mothers with ID experiencing IPV in Atlantic Canada. This study investigates how intimate partner violence and mothers with ID impacted by IPV are conceptualized within the court documents, the ways in which the service system responds to IPV and how IPV is considered within the child welfare decision making process. This study reveals four interrelated themes: Historical vulnerability of the mother, inability to protect the child from abuse, doubly disadvantaged (disability, IPV) and lack of appropriate and inclusive community supports. This study has implications for future research, service provision and policy.

Supporting women and mothers with intellectual disability who have survived intimate partner violence: Guidance for community-based social service workers

David McConnell¹, Shanon Phelan²

¹ *University of Alberta, Edmonton, Canada*

² , ,

Most women with intellectual disability will experience intimate partner violence (IPV) in their lifetime. Without appropriate support services, these women face a heightened risk of experiencing repeated violent victimization and long-term effects, including trauma-related stress and difficulty trusting others. To date, insufficient research has hampered efforts to develop appropriate and effective support services for women with intellectual disability who have survived IPV. In this presentation, we will present findings from an inquiry aimed at generating preliminary guidance for community-based social service providers. This pragmatic inquiry involved a triangulated engagement with feminist relational theory, extant research on the experiences and support needs, priorities and preferences of women with intellectual disability who have experienced IPV, and interviews with experienced social service workers.

The findings of the inquiry suggest that services are best guided by the aim of fostering the *relational autonomy* of women and mothers with intellectual disability, defined as the capability that exists, under socially supportive conditions, to create a desired future and enjoy significant options. One reason for this is to counter the risk of disabling paternalism. Another is to counter the sense of powerlessness that is associated with violent victimization and internalized oppression. Connecting theory to practice, we found that service providers may promote the relational autonomy of women with disabilities who have survived IPV by

applying principles of *reflexivity*, *recognition*, *solidarity* and *safety* to policy and practice. Enacting these principles, service providers may assist women with intellectual disability who have survived IPV with safety planning; securing basic life needs; navigating service systems; strengthening social relationships; acquiring new insight and skills; and, nurturing self-affective attitudes, such as self-trust, that are critical to leading one's own life.

12-05-2023

09:55 - 11:15 - **Childhood disability III - Migration and race** Hilton Nordica meeting room F /

Immigrant families with disabled children: What underlies the services provided ?

Bergljót Borg¹, Unnur Dís Skaptadóttir², Snæfríður Þóra Egilson², Guðbjörg Ottósdóttir²

¹ *University of Akureyri, Akureyri, Iceland*

² *University of Iceland, Reykjavík, Iceland*

In recent years, the number of immigrants has increased rapidly in Iceland. The ongoing study *Migrant Families with Disabled Children* has shown complicated and volatile situation and diverse needs of immigrant families that are not adequately met by services designed to support the them. However, knowledge of how available services are provided and organized is limited. This next part of the study therefore aims to investigate further: a) how the health and welfare services available to immigrant families with disabled children are determined, b) what assumptions underlies the services and c) what prevents it from better accommodating the needs of the families.

The research is guided by critical disability and transnational studies. Focus groups and individual interviews were conducted with service providers. A purposeful sample was used to obtain a broad group of participants who either play a key role in organizing services for immigrant families or work directly with them. Important policy documents in the field were also collected. The data was analyzed using the "What's the Problem Represented to be?" or the WPR approach to policy analysis. With a poststructural perspective, a critical examination was made by inspecting how „problems“ are represented in policies instead of how „problems“ are addressed. The focus is on exploring underlying assumptions and the implication they have on the service and it's outcome.

The scientific value of the study lies in shedding light on the services for immigrant families with disabled children. Despite the increasing use of the WPR approach as policy analysis tool, its application to this particular services is not known. The critical perspective can therefore provide new and important insights into the research topic. At the same time, emphasis will be placed on using the results to promote improvements and innovation in services for immigrant families with disabled children.

Community participation of Arab disabled children and their parents in Israel: Role of family stigma and perceptions towards disability

Shirli Werner¹, Doaa Freg¹, Israa Amer Sarsour²

¹ *Hebrew University of Jerusalem, Jerusalem, Israel*

² *, , Israel*

Community participation refers to involvement in activities providing interactions with others in the community. Community participation of disabled children and their parents is influenced by the stigma directed towards them by others in society. Further, the degree to which stigma influences upon the individual may be related to their own perceptions towards disability. Specifically, individuals adhering to the social (rather than individual) perspective of disability view the marginalization of disabled people as mainly the result of historically created disabling social barriers.

Albeit stigma is known to be culturally-related, few studies investigated stigma and community participation among disabled children and their parents in the Arab community. This study examined whether parents' perception of disability would moderate the relationship between family stigma and community participation of disabled children and their parents in the Arab community in Israel.

Participants were 162 parents of disabled children (aged 5 to 18) from the Arab community. Parents completed a self-report questionnaire which included measures of parental participation (The Israeli Assessment of Participation for Adults), children's participation (Participation and Environment Measure for Children and Youth, PEM-CY), family stigma (FAMSI) and perception towards disability (Dirth's Disability model endorsement).

Family stigma was found to be negatively associated with lower participation among both disabled children and their parents. Social perception of disability moderated this association such that this negative association was only significant among parents holding lower support of the social model of disability. In addition, greater social participation was found among children with sensory impairment (deafness or blindness) and their parents compared to children with intellectual disability or autism and their parents.

We advocate for the development of specific stigma change interventions in the Arab community. It is also important to increase belonging of disabled children and parents within community settings in order to increase their participation.

“I came here to make my family situation better”

Gudbjorg Ottosdottir, Snæfríður Þóra Egilson, Unnur Dís Skaptadóttir

University of Iceland, Reykjavík, Iceland

Historically migration studies and disability studies have shown little interest in disabled migrants. Inspired by Bourdieu's concepts of capital and field, the presentation discusses the social position of migrant families with disabled children in Iceland and their experiences of settlement, employment, family care and services, drawing on findings from a qualitative study. The aim was to explore families' experiences of migration, employment, family care and services for disabled children and families. Twenty-four interviews were conducted with parents from twelve first generation families from southern and eastern Europe, central

America, and Northeast Asia with a total of sixteen disabled children aged two to seventeen. Parents were recruited through a purposive sampling method. Interview transcripts were analysed using an inductive coding technique that highlighted and analysed themes and subthemes in parents' experiences in relation to capital and field and how family's social position may be determined by the social, cultural, and economic capital they had lost and remade in the migration process. The findings show that families faced various barriers in their daily life, in juggling work and family care because of limited possibilities to build cultural, social, and economic capital linked with their social position. The findings highlight strategies parents used in their efforts to build social and economic capital. The study depicts the importance of considering diverse situations of migrant families with disabled children, including their knowledge of local language, employment position, relationships with services and access to informal support, which impacted on their abilities to generate and make capital.

Experiences of Professionals Working with Migrant Families who have Disabled Children

Sibeso Imbula,

Reykjavík Municipality, Reykjavík, Iceland

This qualitative study focuses on experiences of welfare service professionals working with migrant families who have disabled children aged 6 to 16 years. Five professionals who work with migrant families in diverse settings of the welfare service system participated in the study. The professionals are employed by Reykjavík City, are of different ages, and have a variety of professional backgrounds and work experience. The data was gathered through semi-structured interviews conducted in English, and each lasted for about 60 minutes. The findings reveal two main categories: the challenges encountered by the welfare service professionals working with migrant families and recommendations for improving services to meet needs of migrant families. Findings also indicate that miscommunication and misunderstandings are common in professional-family interactions, and the involvement of interpreters complicates matters. Professionals also indicate that migrant families face barriers in accessing information and services. Migrant parents also encounter many obstacles due to cultural differences, small networks and less access to information, resources and staff.

12-05-2023

09:55 - 11:15 - **Policy and theoretical perspectives V - Intersectionality** Grand Hotel - Gullteigur B /

Intersectional shielding and passing

Sara E. Sellevold Orning,

University of Oslo, Oslo, Norway

The notion of intersectionality is increasingly enriching disability studies. First, the concept of intersectionality allows us to see how disabling processes interact with other forms of social exclusion, related to race, gender, ethnicity and so on. Second, intersectional theory also allows us to see how these interactions are, in fact, interactions between various social hierarchies. This also adds to the theoretical repertoire of disability studies, highlighting how disabling processes are an unjustly disabling factor in some people's lives but also an equally unjustly enabling factor in the lives of others.

While intersectional perspective are mainly applied to the “adversive end” of these processes, the project “disabling processes and intersectional protection” sets out to develop a notion of *intersectional shielding*. In order to bring this notion closer to classical notions in disability studies, this presentation aims to consider how notion of intersectional shielding relates to the notion of passing. Using insights from intersectionality's emphasis on situated knowledge, this presentation emphasises the interactions between disability, gender identity, and racialisation. I first look at how passing in these three examples embodies normalising effects as far as it allows for an approximation to a white, cis male norm. As such, the concept of passing entails emphasis on some features over others, especially with reference to normatively accepted identity categories. Then I move on to a further conceptualisation of intersectional shielding, which roughly translates to consciously using the features of an identity category higher in the socio-medico-cultural hierarchy to mask a more stigmatised identity category. Finally, a comparative discussion paves way for the argument that passing implies assimilation while intersectional shielding provides protection.

Theorizing intersectional shielding

Halvor Hanisch,

Oslo Metropolitan University, Risør, Norway

The notion of intersectionality is increasingly enriching disability studies. First, the concept of intersectionality allows us to see how disabling processes interact with other forms of social exclusion, related to race, gender, ethnicity and so on. Second, intersectional theory also allows us to see how these interactions are, in fact, interactions between various social hierarchies. This also adds to the theoretical repertoire of disability studies, highlighting how disabling processes are an unjustly disabling factor in some people's lives but also an equally unjustly enabling factor in the lives of others.

In empirical terms, the term is mainly applied to the “adversive end” of these processes. There is, for instance, a large body of research on the impact of poverty in the lives of people with disabilities, but very few attempts to research how wealth play out in these contexts. Similarly, research on the intersection between disabling processes and racialization rarely deals directly with the importance of whiteness in the lives of people with disabilities.

Following the methodological roots of the concept of intersectionality – which often has emphasized personal, embodied experiences – this presentation reports from the autotheoretical project “disabling processes and intersectional protection”. The purpose of the project is to develop a notion of *intersectional shielding*. Hopefully, a more developed notion of intersectional shielding will allow us to (1) widen the empirical scope of intersectional disability studies, (2) explore how one axis of oppression interacts with another form of privilege, and (3) glimpse a brutality in disabling processes that we often forget if we take intersectional shielding for granted.

Settlement and integration of refugees with disabilities and high support needs in Norway: Contextual review and study of local settlement authorities

Berit Berg, Stian Thoresen

NTNU Social Research, Trondheim, Norway

Refugees and asylum-seekers experience many vulnerabilities, including poor mental health, psychosocial and other disabilities. It may be challenging to identify and diagnose these challenges, as individuals may be reluctant to disclose in fear of adverse impact on settlement prospects, limited health literacy, communication challenges, and poor flow of information. Many refugees and asylum-seekers may share such challenges and experiences, but persons with complex or high support needs may be particularly vulnerable. Recognising that refugees with disabilities and high support needs are diverse with diverse needs, there is a dearth of research concerning the impact of health status or health information on refugees' settlement and the interrelated vulnerabilities regarding integration. However, multiple reports have questioned this knowledge gap, illuminated tangential issues, and argued for enhanced understanding of the underlying and interrelated issues.

This presentation presents findings from a recently completed study funded by the Norwegian Ministry of Labour and Social Inclusion to enhance our knowledge concerning refugees' health status and the impact on the settlement process. It will highlight the challenges and paradoxes of current policies and practices by presenting a publicly known case. The case illustrates how individuals with very high support needs may be caught in indefinite limbo without prospects for settlement in a municipality, despite having been awarded settlement. Instead of being on a trajectory of integration and settlement together with family and social networks, the bureaucracies can "trap" persons with disabilities and high support needs in the reception system. The paradox is that this is not a cost-saving approach, but may actually be a more costly option. The presentation will also present barriers and facilitators for settlement and integration, drawing on attitudes and experiences among local settlement authorities in the municipalities.

Migration histories, contemporary bordering practices: the intersection of migration studies and disability studies

Nicola Burns,

University of Glasgow, Glasgow, United Kingdom

In this paper I seek to engage with recent debates within migration studies around the place of colonialism within migration. Engaging with the work of Mayblin and Turner's (2021) "Migration Studies and Colonialism", the paper outlines their key arguments around the invisibility of colonialism and racism within migration histories and what this means for the study of migration. I reflect on the importance of these arguments in the context of disability studies and its continuing research on migration stories of disabled people, recording the

ways in which disablist and racist logics have sought to exclude and expel particular bodies and minds from sovereign states. Within migration studies, the use of disability within bordering practices is rarely commented upon, as dominant discourses eliding health and disability obscure the categorisation of disability within immigration and asylum systems globally. The importance of this invisibility within migration studies is reflected upon in the context of Mayblin and Turner's argument.

The paper turns to what the implications of such theoretical engagements mean in the context of working in this field of study. The paper considers the implications of recognising colonial histories in contemporary migration experiences in research practice, bringing together scholarship and practice from these two disciplines. Considering recent calls for decolonisation within academia, the remainder of the paper concerns itself with the study of disability and migration in the field, asking in what ways can disability studies and migration studies inform future work. Drawing on an ongoing collaboration with disability and migrant rights organisations to develop research, the paper reflects on the challenges of decolonising the field of study.

12-05-2023

09:55 - 11:15 - **Education II - Technology** Grand Hotel - Muninn /

Tensions between inclusion technologies and the rights of persons with disability in Chilean higher education.

Marta Infante,

Pontificia Universidad Católica de Chile, Santiago, Chile

This presentation is part of a larger study that seeks to map the modes of discursive and material production of dis/ability in Chilean universities that develop educational inclusion programs.

During the last decades, and in accordance with the Chilean State commitment to the Convention on the Rights of Persons with Disabilities (CRPD), various universities have developed specific policies and practices to ensure the equal rights and advancement of students with disabilities.

The specific aim of this presentation is to expose the emerging material-discursive tension between the desire of inclusion and the ableist neoliberal technologies in Chilean higher education. Framed by an analysis of affective inclusive technologies for disabled students at universities, I use Deleuzoguattarian assemblage theory to map the expression of a dis/ableist onto-epistemology that interferes with the rights of persons with disabilities. Particularly, through the interrogation of universities' production of audio-visual material and curriculum design, the dis/abled student is theorized as the subject of an ableist affect that order non-normative subjectivities. As I do this, I expose the semiotic-material relationships that regulate and condition the learning experiences and possibilities of students with disabilities in higher education.

Collaborative music-making with Special Education Needs students and their assistants: A study on music playing among preverbal individuals with the Funki instruments

Maria Svahn¹, Josefine Hölling¹, Hans Lindetorp², Emma Frid³, Kjetil Falkenberg³

¹ *Funki/KTH Royal Institute of Technology, Stockholm, Sweden*

² *Royal Academy of Music, Stockholm, Sweden*

³ *KTH Royal Institute of Technology, STOCKHOLM, Sweden*

The field of research dedicated to Accessible Digital Musical Instruments (ADMIs) is growing and there is an increased interest in how different accessible music technologies can be used to promote diversity and inclusion in music-making. Researchers currently voice the need to move away from a techno-centric view of musical expression and to focus more on the sociocultural contexts in which ADMIs are used. In this study, we explore how “Funki”, a set of ADMIs developed for students with Profound and Multiple Learning Disabilities (PMLD) can be used in a collaborative music-making setting in a Special Educational Needs (SEN) school, together with assistants. Previous findings have suggested that the musical interactions taking place, as well as the group dynamics, were highly dependent on the session assistants and their level of participation. It is therefore important to consider the active role of assistants, who may have little or no prior music training. The instruments provided should allow the assistant to not only help the students in making music but also enable the assistants themselves to create sounds without interfering or disturbing the sounds produced by the students. In the current work, we show how the Funki instruments could be expanded with WebAudioXML (waxml) for mapping user interactions to control music and audio parameters and make it possible for assistants to control musical aspects like the tonality, rhythmic density, or structure of the composition. The system was tested in a case study with four students and their assistants at a SEN school, including semi-structured interviews on how Funki supported inclusive music-making and the assistant’s role in this context. The findings of this work highlight how ADMIs could be conceptualized and designed to include special education teachers, teaching assistants, and other carers more actively in collaborative music-making.

A Cyborg’s Dream: Telepresence teaching in Higher Education

Sophie Savage, Tillie Curran

University of the West of England, Bristol, United Kingdom

This presentation shares my experience of piloting the use of a telepresence robot as a reasonable adjustment for teaching in higher education during the COVID-19 pandemic. I taught from home using the robot to facilitate interactive social science seminars.

The three themes identified from my autoethnographic analysis: inclusion, relationships and sense of self and value are discussed using post-human discourse adopting the viewpoint of the cyborg. Where technology is used as an extension of the self, the cyborg narrative challenges dominant discourses of technology that are framed as ‘assistive’. Therefore, centring the experience of a disabled person, in this case, myself, is key in understanding ‘virtual embodiment’ and the impact upon my identity during a time hailed as ‘post-COVID’.

In addition, this pilot gave students who had previously only interacted with me online the opportunity to meet me in their teaching room. Their feedback emphasised the quality of the

teacher-student relationship that telepresence enabled and their learning about inclusion. Students highlighted the importance of having disabled academics in their learning environment and valued this direct experience of inclusive practice through technological innovation.

Myself and my co-author reflect on the institutional barriers encountered and propose strategies for the wide-scale rollout of telepresence as a reasonable adjustment for staff and students. I have dreamed of fleets of telepresence robots being available in all public spaces, added to the menu of options to access a full life. The cost of not supporting this cyborg dream, we suggest, is not a financial one but an ethical and human one. Investment in supporting disabled people's right to work and right to a full life can be a practical demonstration of ethical rigour and aligns with the shared missions of equality and diversity present across all higher education institutions.

Teaching with, through and about disability: transformative learning in digital accessibility education

Andy Coverdale, Sarah Lewthwaite

University of Southampton, Southampton, United Kingdom

As digital technologies continue to dominate everyday life, there is a critical need to develop accessible tools, platforms and services. As digital accessibility is a complex topic, with technical, legal and social dimensions, teaching approaches vary. An enhanced awareness and understanding of disability are pivotal to learner progression. However, it can be challenging to teach the nuanced conceptual and lived aspects of disability alongside the procedural knowledge and technical skills necessary to build inclusive technologies.

In this paper, we explore digital accessibility education and the centrality of teaching with, through and about disability in this field. From an ongoing 5-year project exploring accessibility pedagogy, we draw on research interviews, focus groups and case studies with educators, learners, expert users and user-groups working together in university and workplace settings. Here, we focus specifically on the perspectives of disabled experts and end-user communities engaged in teaching.

In technology-focused disciplines, we find that culturally embedded practices such as simulation and the use of fictional personas endure. Yet such approaches fail to convey the social, emotional and embodied dimensions of disability, trivialising the digital barriers that many experience everyday. In contrast, direct engagement with individuals, groups and experts with disabilities is found to be effective and transformative for learners. When challenging assumptions and biases and providing authentic experiences of disability, disabled educators are found to actively deploy a range of pedagogic strategies and tactics to foster a nuanced understanding of disability and technology. At the same time, collaborating with disabled experts and users on problem- and project-based learning activities promotes communication competencies that are valued in higher education and industry for all groups involved. This also prompts us to consider the teaching and learning of accessibility within the wider contexts of inclusive and participatory practices in the design and development of digital technologies.

12-05-2023

09:55 - 11:15 - **Culture and history II - Representations** ÖBÍ 2 - Sigtún 42 /

Showing the invisible. Imagery of chronic pain in social media self-representations.

Rouven Seebo, Lisa Pfahl ,

Universität Innsbruck / Institute of Educationl Science, Innsbruck , Austria

Images of disabled persons are widespread in mass media, but they are relatively rare overall, as studies on media representations show (e.g. Pernegger 2016). These images influence the way others see disabled bodies and the way disabled persons see their own bodies. Barnes categorizes the representation of disabled persons in visual media as follows: "The Disabled Person as Pityable and Pathetic [...] as Super Cripple [...] [and] as Burden". Besides that, there are also examples of depictions that show disabled people "as normal" (Barnes 1992). However, showing disabled persons as 'normal' can have inclusive effects on the one hand, but on the other hand it may create a "nonidentity" (McRuer 2006). How can daily general and political struggles with barriers and hidden ableist discrimination become visible without reproducing stereotypes of 'the disabled'? Social media offer the possibility to communicate one's bodily feelings with others in communities and to share experiences (Cocq & Ljuslinder 2020).

In this oral conference presentation, we will contrast the analyses of two social media posts in which people portray their experienced disability in the context of chronic pain, a phenomenon that is normally considered invisible. Using these two examples, we show a connection between aspects of individualization in the form of a medical diagnosis and a collective claim by trying to achieve acceptance for other persons with disability experience. In the analysis, we combine sociological (Lindemann 2020) and anthropological (Plessner 1982) theoretical approaches to explore how images of disabled persons raise questions about living in freedom and dignity in modern society. We conclude by presenting reflections on a theorization of the disabled body.

References

- Barnes, C. (1992): Disabling Imagery and the Media.
- Cocq, C. & Ljuslinder, K.(2020): Self-representations on social media.
- Plessner, H. (1982): Der Mensch als Lebewesen.
- Lindemann, G. (2020): Die Ordnung der Berührung.
- Mc Ruer, R. (2006): Crip Theory.
- Pernegger, M. (2016): Menschen mit Behinderung in österreichischen Massenmedien.

Midgetism: Exploring the exploitation and discrimination experienced by people with dwarfism

Erin Pritchard ,

Liverpool Hope University, Liverpool , United Kingdom

People with dwarfism experience oppression and discrimination which are informed by both heightism and disablism, and thus separately these terms cannot really demonstrate the

discrimination experienced by people with dwarfism. Drawing on findings from my forthcoming book, *Midgetism: the exploitation and discrimination of people with dwarfism*, this paper introduces the term *Midgetism*, to aid in exploring the oppression and discrimination people with dwarfism experience. In particular, the book engaged with autocritical discourse analysis, to highlight some of the lived experiences informed by midgetism, which will be used to exemplify some points within this paper. Furthermore, the paper draws on the book's argument as to why the term midget, when referring to a 'midget entertainer', should be reclaimed and repurposed for analytical and advocacy purposes only. It is argued that midget entertainment is a key factor in reinforcing midgetism within society. Particular reference is made to the problematic assumptions, held by average-sized people, who claim that midget entertainment is an acceptable form of employment for people with dwarfism, exposing the socially constructed inferior standing of them within society. These beliefs are reinforced when midget entertainers consent to partaking in entertainment which is reinforced by midgetism.

Towards an Inclusive Future? Disability, Genetic Engineering and Eugenics in Star Trek

Josefine Wälivaara,

Umeå University, Umeå, Sweden

Rosemarie Garland-Thomson (2017) argues that two world building initiatives are currently in progress in modern cultures: *inclusive world building*, which seeks to include people with disabilities as valued parts of society, and *eugenic world building*, which aims to “eliminate disability and, along with it, people with disabilities from human communities and future worlds” (134). Alison Kafer (2013) contends that it is often taken for granted that a valued and desirable future is a future without disability (3). In stories about the future in the genre of science fiction, disability is often omitted, eradicated, or present only to be cured by imaginative future medical or technological advances (Wälivaara 2018; Cheu 2002; Schalk 2019). Images of the future are closely intertwined with norms of the present, reflecting, and often perpetuating normative views and ableist values (Wälivaara 2018; Allen 2013). This paper investigates one such image of the future, the television series *Star Trek*. The aim of the paper is to analyze how disability is valued/de-valued in the fictional future of the series by using Garland-Thomson's two world building initiatives to explore it in terms of inclusive or eugenic futures. The vision of the future portrayed in the *Star Trek* universe is characterized by a progression into an egalitarian society, in which for example racism is considered “a regrettable relic of the past” (Gregory, 2000). *Star Trek (TNG)* has been described as deploying a type of “deep-space multiculturalism”, an ethic that values diversity (Weinstock, 1996). While there are several instances when the series explicitly takes a stand against eugenic futures, I argue that looking specifically at themes and storylines of genetic engineering also reveals ableist values and eugenic ideals.

(Re)Construction(s) of Disability and Vulnerability in Media “Realities” during the Covid-19 Pandemic

Sabine Mandl, Barberi Alessandro

Bertha von Suttner Private University , 3100 St. Pölten, Austria

Discourses constitute knowledge, create supposed realities, and points of orientation, which in turn generate or reinforce normality, normalizations and normativity. Media, as central sphere of public discourses (re)produces images and attributions through its mass communication channels and thus has a vast impact on society and culture. Media contribute significantly to “what is to be considered as ‘normal’ and ‘not normal’, what is considered as sayable (and doable) and what is not” (Jäger/Jäger 2012, p. 161). In the context of the research project *Cov_enable* (P 34641), funded by the Austrian Science Fund (FWF), we raise the question whether and in which way people with disabilities were presented in the mass media as so-called “vulnerable group” during the Covid 19 pandemic. In doing so, we tried to reconstruct the concepts of vulnerability and disability that have been used in media coverage on the basis of selected online newspaper articles (of an Austrian premium newspaper) as well as television broadcasts (of the Austrian Broadcasting Cooperation, ORF) during the pandemic. By employing critical discourse analysis “media realities” can be reconstructed while revealing power relationships at the same time. Based on the sampling category “disability” online newspaper articles and TV broadcasts were selected. The subsequent analysis was embedded in a larger discourse on “vulnerability” and aimed at reconstructing the images and attributions inscribed in the media releases during the pandemic by following guiding criteria, such as thematical framing, spatial and social context, and the use of language and images. The paper frames the results of the analysis in the normative context of the human rights model of disability and the rights enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Thereby we shed light on how the constructions and bodies of knowledge inscribed in the media discourse correspond to the UNCRPD.

12-05-2023

09:55 - 11:15 - **Childhood disability II - Children's rights and disability** Hilton Nordica meeting room D /

Social media ethnography: Content analysis of posts by parents of children with autism

Kathleen McGoldrick¹, Sharon Cuff²,

¹ *Stony Brook University, New York, United States*

² *StonyBrook University, StonyBrook, United States*

Social media ethnography: Content analysis of posts by parents of children with autism

“Children with disability are rarely considered the owners of their private information. From their parents to charity organizations the private lives of children with disability are considered public domain” (Goggin, & Ellis, 2020, p. 221). Sharenting is the posting of child-centric material by parents on social media (Steinberg, 2017). As many as 98% of parents on Facebook have shared at least one photo of a child (Bartholomew et al., 2012). The purpose of this social media ethnography was to use the disability studies (DS) theory as a lens to seek a nuanced and rich understanding of the content of social media posts by parents who include their child’s disability in their usernames and/or biography on public social media platforms.

Publicly accessible data was collected from 19 Twitter and TikTok accounts posted between 2019-2021, including narrative and multimedia content (e.g., video, audio, pictures), and entered into NVivo 12 for analysis. Disability studies theory was used to perform the qualitative content analysis (QCA). Two people (KM & SC), with extensive knowledge of the DS philosophy, worked together to analyze the data until agreement was reached. A third person (DZ), with only a basic familiarity in the subject matter, served as a peer reviewer, working independently using the code book and data sample to review.

Identified themes were identical between coders. Two distinct social ethnographies were identified: those that uphold the principles of disability studies and those that reject them. While the textual and visual datum aligned with one culture, the individual posters crossed both. Identified opposing yet parallel norms were Affirming or Labeling, Recognizing Independence or Infantilizing, and Integrating or Pathologizing.

Children's Rights and Disability

Angharad Beckett,

University of Leeds, Leeds, United Kingdom

In this introductory paper, we discuss the ways in which the concepts behind the three keywords of these two sessions – children, rights and disability – have evolved, especially in the past decades and consider the intersection of the three. We then discuss how the study of disabled childhoods has widened from a narrow consideration of assessing impairment and functional ability to investigating the impact of disabling barriers on disabled children. The variety of literature in disability studies on the lives of disabled children is discussed to provide a context for the rest of the papers in these two complementary sessions.

They still need to listen more': Working in partnership with disabled young researchers to inform and shape country submissions to the UNCRPD and UNCRC Committees

Zara Todd, Anita Franklin

Independent Researcher , Portsmouth, United Kingdom

Disabled children and young people have the right to express their views freely on all matters affecting them. This is enshrined in United Nations (UN) Conventions serving both children (CRC) and disabled people (CRPD). However, this right is rarely recognised and enacted. Adult-focused agendas can dominate discourses on the CRPD and, within the CRC, it is also still evident that the rights of disabled children can be side-lined in a full agenda aiming to meet rights obligations for all children. Therefore, it is of critical importance that we share ways of working which enable the empowerment and engagement of disabled children and young people in human rights monitoring processes, and within all arenas where decisions concerning access to human rights are discussed.

This paper discusses a practical, empowering, rights-focused methodological framework which, if adopted, would enable State Parties to empower disabled children and young people to lead submissions to the UN. This framework emerged from a study, led by a disabled young researcher collective, which gathered evidence to inform England's Children's Commissioner's submission to the CRPD and CRC. This case-study illustrates

the potential for disabled child and young person led research, where emancipatory, rights-focused values and mechanisms are in place which empower disabled children and young people to demonstrate their skills, knowledge, and commitment to lobbying for social justice. Through research training, disability rights consciousness raising, and supporting disabled children and young people to gather and utilise research evidence, we challenge the invisibility of disabled children within arenas of discussion, and decision-making, of policy. We also contest the often-held assumption that disabled children neither lack the capacity nor skills to lead work which can have an important influencing effect on government and non-governmental human rights reporting processes.

12-05-2023

09:55 - 11:15 - **Deafness II with International Sign Language - Accessibility and support** Grand Hotel - Háteigur /

Equal access to mental health services? Reflections from young Norwegian adults with hearing impairments

Patrick Stefan Kermit¹, Katie Kåsa Moriggi², Anja Helene Hansen³

¹ *Norwegian University of Science and Technology, Trondheim, Norway*

² *Mental Helse Ungdom, Oslo, Norway*

³ *Oslo University, Oslo, Norway*

Background:

This paper presents a health service research project studying the encounters between young people with hearing impairments and mental health services. Hearing impairment is believed to be a risk factor for mental health problems. It is thus important to learn more about how mental health services should accommodate young people seeking help.

Research question:

“What are the needs for mental health services experienced by young people between 16 and 25 who are hearing impaired? And what are their experiences with seeking and obtaining such services?”

Method:

The research team have applied qualitative methods and conducted interviews with 18 young people with hearing impairment, asking them about their experiences in the context of seeking mental health services.

Results:

The principal result of the study is that the participating informants saw Norwegian mental health services as services designed to suit typical hearing people primarily. When young people with hearing impairments seek or need mental health services they encounter the same barriers that prevent them from experiencing equity in society in general.

Discussion:

The results shed light on the constant and extraordinary cognitive and emotional work the informants must carry out in order to bridge the gap between that which is offered by the mental health services and that which is needed. Important here, is that the informants did not regard their principal needs as individual needs for technical adjustments, such as interpreting. On the contrary, the informants clearly articulated the expectations that they should be met by health services that could understand them as ordinary young people, and as individuals with singular life experiences as persons with hearing impairments. This is a result shedding light on the need for an inclusive health service, and the implications of these results are discussed.

In Denmark deaf people have free access to professional social counseling in their mother tongue

Anne-Dorte Krogh²,

¹ *CFD Rådgivning, Viden og Udvikling, Søborg, Denmark*

² *CFD Rådgivning, Viden og Udvikling, København, Denmark*

This presentation will introduce a unique social service for deaf people and how it is organized. In Denmark *The Consultancy for Deaf People* offers nationwide specialized social consultancy service for adult deaf people. The consultancy is publicly founded but run by the private non-profit organization CFD. The service has existed for more than 80 years and the right to this service is written in the Danish law for social services. Thereby the right to free and equal service in this arena is guaranteed both legally and economically for deaf people. The service has no parallel, servicing people with other kinds of disability in Denmark.

Social counseling with a holistic approach

The Consultancy for Deaf People offers comprehensive counseling on a number of topics within the social field:

Occupation

Education

Societal aspects (legal rights)

Family counseling (for deaf parents)

Elderly counseling (for elderly sign language speakers)

Mental vulnerability and illness (counseling about support options for people with psychological and psychiatric problems)

Refugees (counseling both for the individual and the institutions that receive refugees)

The Consultancy for Deaf People also provide counseling to municipalities, employers, educational institutions and other professionals who are in contact with people who are deaf.

Consultancy in sign language by well-educated employees

The employees in *The Consultancy for Deaf People* communicate directly with users of the consultancy service in sign language or Danish with support signs depending on the language code required by the user. Several of the employees are themselves deaf and native speakers of sign language.

The employees are social workers or pedagogues. They have a broad professional knowledge in legal, societal and labor market issues as well as specialist knowledge of the societal conditions for people who are deaf.

Exploring the role of face masks during the COVID-19 pandemic through perceptions of disabled and deaf students in schools.

Barbara Hager, Alexandra Gutschik, Michael Doblmaier

University of Vienna, Vienna, Austria

The COVID-19 pandemic had sudden and far-reaching impacts on educational systems all over the world. This presentation highlights temporary results of the ongoing Austrian research project *Cov_enable: Reimagining vulnerabilities in times of crises* (Austrian Science Fund FWF, P 34641). It deals with the effects of the COVID-19 pandemic on students with disabilities and deaf students in Austrian schools. In addition to analysing COVID-19-related policies, students were interviewed and instructed to regularly document their experiences in the form of videos in Austrian Sign Language or in German and short texts.

The political handling of the pandemic has so far shown different political styles, all leading to an (partly) ableist and audist approach. In Austria, measures against the spreading of COVID-19 were adopted for everyone, with exceptions for certain groups of people. Regarding education in schools, the diversity of students has not been sufficiently addressed to ensure equal access to inclusive education and avert negative effects, resulting in severe consequences, especially for students with disabilities and Deaf students. Necessary adaptations in regulations were often delayed and mainly meant exceptions to the regulations.

Exceptions for compliance with distance rules and COVID-19 testing at schools, on site-classes for students with disabilities during general distance-learning phases and removal of the face mask obligation are some examples of the exemptions available to students with disabilities and Deaf students.

This presentation explores the role of face masks using first-hand accounts. While general mask requirement enables a common approach to the pandemic these measures also produce emphasize and manifest the exclusion of certain groups, e.g. Deaf students. We examine how the regulations are experienced by students and which role face masks play in students' perceptions of the pandemic. The presentation also explores what adjustments to the regulations would be needed to create more inclusive management of future crises.

The Acquisition of Swedish Sign Language by a Deaf man with Down syndrome

Pia Simper-Allen,

Stockholm University, Stockholm, Sweden

Disabled people's communication and language acquisition are often seen as a disorder or described as deviant instead of as an individual's variant of a language with its unique characteristics. This variation among deaf signers is many. Still, one major cause for this variation is whether they have got sign language input from early childhood from native or native-like sign language users or not. Another cause for sign language variation is if an individual has a condition such as autism or Down syndrome. Very little sign language linguistics research to date has been done on this group. The existing research has mainly

focused on sign acquisition of deaf children with autism (Shield & Meier 2014) and modality issues in hearing twins with Down syndrome to deaf parents (Woll & Grove 1996). Shield & Meier (2014) describe sign acquisition in individuals with autism and how this condition affects sign language acquisition, i.e., difficulties with perspective-taking, use of fewer non-manual components, lack comprehension of facial expressions, and articulatory problems in their signs.

This presentation builds on an analysis of a deaf man's, with Down syndrome, sign language skills in Swedish Sign Language (STS) and will be described from a positive language-variation framework. The focus will be on the early sentences, use of non-manual features, e.g., marking questions, manual alphabet, perspective-taking in narratives, and linguistic awareness. The study is a longitudinal case study of a deaf man who has grown up with STS as his first language. Data comes from video recordings (age 3 to 6, 16 to 22) from interaction in a bilingual nursery (STS and Swedish) and recorded narratives by the man. The presentation will conclude with the importance of further research on sign language variants in deaf individuals with cognitive disorders and analyse their communication from a positive language-variation framework.

12-05-2023

09:55 - 11:15 - **Covid-19 II / Inclusion and the body - Participation and inclusion** ÖBÍ 1 Sigtún 42 /

Experiences of accessing education among people with disabilities during the COVID-19 pandemic: Evidence from 5 low- and middle-income countries

Hunt Xanthe¹, Hameed Shaffa², Rifat Khan³, Luong Anh Ngoc⁴, John Ganle⁵, Shailaja Tetali⁶, Lopita Huq⁷, Tom Shakespeare², Zeynep Ilkkursunl'm⁸, Ceren Acarturk⁸, Banks Morgan²

¹ Stellenbosch University, Cape Town, South Africa

² London School of Hygiene and Tropical Medicine, London, United Kingdom

³ BRAC University, Dhaka, Bangladesh

⁴ Hanoi Medical University, Hanoi, Vietnam

⁵ University of Ghana, Accra, Ghana

⁶ Indian Institute of Public Health-Hyderabad, Hyderabad, India

⁷ BRAC Institute of Governance and Development, Dhaka, Bangladesh

⁸ Koc University, Istanbul, Turkey

The COVID-19 pandemic has had profound impacts on education globally. School closures – particularly in the first year of the pandemic – were widespread, intermittently sending children home for long periods of time in an attempt by governments to reduce transmission. When it comes to education, children and young people with disabilities face extensive barriers to educational inclusion, participation, and attainment, and these issues predate the pandemic. Emerging evidence suggests that the pandemic may have widened educational disparities between children with and without disabilities. However, there is not a great deal of literature presenting accounts of the lived experiences of people with disabilities in LMIC regarding their education during Covid-19 pandemic. We administered surveys to people with disabilities in Bangladesh, Ghana, India, Turkey, and Viet Nam between 2020 and 2021.

Between 20 and 60 people with disabilities were interviewed in each site. Data were analysed using thematic analysis. Our findings revealed that barriers to educational access and participation for people with disabilities were numerous. However, they often reflected the exacerbation of existing difficulties by the pandemic, more often than they presented wholly new ones. For instance, cost and accessibility - two major challenges facing people with disabilities in education prior to the pandemic - worsened. There was also evidence that the pandemic response created new challenges for people with disabilities, differentially negatively affecting them compared to people without disabilities. For instance, children with disabilities suffered negative consequences from losing access to the structured environment of school, and losing access to therapies that were delivered as part of a package of services through the school. The findings are discussed in respect of how they can be used to inform proactive strategies to respond to the needs of people with disabilities in the face of emergencies.

Co-designing future working life for people with disabilities – Learning from experiences gained during the Covid-19 pandemic

Jörgen Lundälv¹, Magnus Eriksson², Elisabet M Nilsson³

¹ *University of Gothenburg, Gothenburg, Sweden*

² *Research Institutes of Sweden (RISE), Gothenburg, Sweden*

³ *Malmö university, School of Arts and Communication (K3), Malmö, Sweden*

The multidisciplinary research project “Working life during Covid-19 pandemic: social participation, learning experiences, design opportunities and future work life for people with disabilities” aims to explore how experiences gained from the Covid-19 pandemic can improve the conditions for people with various forms of disabilities to participate in and contribute to working life. The project builds on a collaboration with a network of stakeholders from organisations representing people with disabilities and assumes a participatory research and design research approach where prototyping and design activities are part of the iterative research process. This is manifested by inviting our stakeholders to be part of an exploratory collaborative (co-)design process where new knowledge is generated through various design-oriented activities. The research and design process consists of three exploratory phases (Discover, Define, Develop), and one concluding phase (Deliver).

In this presentation, we will present insights gained from the first two phases of the design and research process. 23 people with various disabilities (motor, visual, hearing, neuropsychiatric impairments) were interviewed about their working life. Based on the interviews, we developed an understanding of what strategies they used to adapt to the pandemic situation, and how they handled stressful situations. The participants were also asked to describe and document their workplaces, a typical working day, and what role tools and technologies played in achieving or preventing full participation in working life. By analysing their individuals' stories, different strategies for coping with the situation were identified, and which of these strategies have proven to be more or less successful to apply in working life. These insights may contribute to designing work conditions for people with disabilities to partake in future working life, which is characterised by inclusion and social participation on equal terms.

Resisting Emergency: Disability and the University

Kate Kaul,

York University, Toronto, Canada

The COVID-19 pandemic has been both a real tragedy, taking and altering lives across the world, and an opportunity for “emergency thinking,” in which concerns with social justice are routinely suspended. What does it mean when teaching is declared an emergency? Set in the context of precarious teaching in the Canadian academy, my paper tells a story about the implications for justice – for teaching justice, for teaching justly – of the recent declarations of emergency. Precarious work and disability have always been framed as emergencies: emergency postings, departmental need, accommodations only so long as they are “reasonable”. The current universalization of emergency – representing it something that all of us have in common – presents new challenges for transgressive teaching. Disabilities, for students and for teachers, move in and out of visibility as we move from the classroom to online, and back, and back again. Disability justice also shifts in and out of visibility. Teaching transgression, in this situation, demands new work, new labour, as we push to keep disability and access, and disabled lives, centred in teaching and/as advocacy work.

My discussion uses two key texts, Elaine Scarry’s book, *Thinking in an Emergency* and Kelly Fritsch’s keyword essay, “Accessible”. It also builds on my own discussion on risk and precarity in my chapter “Risking Experience: Disability, Precarity and Disclosure”. Aime Hamraie’s article, “Universal Design and the Problem of ‘Post-disability’ Ideology” is also important to my consideration of the ways that emergency, crisis, and disability are read in relation to one another. During the first two years of the pandemic, especially, emergency was “universalized” and disabled academics (students, staff, faculty) were re-situated, with some of the accommodations they had long fought for, suddenly available to everyone: flexible working hours, working from home, working online. More recently, the insistent return to “normal” conditions – on Canadian university campuses, long before any testing showed that this might be safe – is demanding different ways of thinking about disability, care, and emergency on (and off) campus. More broadly, the paper draws on the theoretical framework of my dissertation and, especially, W.G. Sebald, G. Agamben, M. Bakhtin, J. Butler, M. Foucault et al in relation to ways of thinking about disaster, emergency, and subjectivity.

Vocational Rehabilitation in Germany during the Covid-19 Pandemic

Nancy Reims, Angela Rauch

Institute for Employment Research, Nürnberg, Germany

The Covid-19 pandemic has posed new challenges to actors in vocational rehabilitation (VR). In this study, we are interested in the following: How did actors like VR participants, service providers and financers of VR experience the Covid-19 pandemic, which process changes and delays have occurred, and what impact will this possibly have on the inclusion of people with disabilities?

Within guided expert interviews, we asked service providers of VR programs (n=16) between July 2020 und July 2021 about their experiences during the Covid-19 pandemic. Additionally,

we interviewed representatives of the Federal Employment Agency (n=3), individuals from three employment agencies and two job centers as well as two persons in VR.

VR programs had to be conducted remotely. Especially smaller service providers had to create the digital possibilities first. Furthermore, there were also technical difficulties as well as social and health-related issues on the part of the participants. Thus, continuous additional support by the service providers was indispensable to contain psychological crises, to ensure the understanding of the program contents and to avoid dropouts. However, the - forced - digitalization of VR was also an advantage as e.g. long-distance communication as well as part-time/interrupted qualification becomes easier.

The employment agencies and job centers closed their doors for a long time. Since schools were also closed, VR and general vocational counseling did not take place as well as the assessment procedures for determining VR needs. Thus, a decline in VR access is already emerging. As seen elsewhere, individuals from poor households may be more likely to be affected because they are more difficult to keep in touch. Even though much of the qualification during VR could be done in alternative ways, experience from the pandemic has shown that VR largely requires face-to-face contact, especially for young people and individuals with psychological disabilities.

Short and locked down: The effects of COVID-19 on a woman with dwarfism

Clare Harvey,

University of the Witwatersrand, Johannesburg, South Africa

Living with a visible physical disability – specifically dwarfism – brings psychosocial challenges. Living through the COVID-19 pandemic amplifies these dwarfism-related complexities, exposing the politics of visibility and exclusion, as well as spatial injustices. This autoethnographic paper deliberates the multi-layered experiences of these heightened disabling encounters. The legality of wearing, and conversing, through face masks with people much taller than me creates a strain on communication and connection. Spatial separation and a sense of alienation ensue – a disability lens of distance is apparent. The discriminatory physical spaces which people with dwarfism endure are more disabling because of the pandemic. Perspex screens aggravate prevailing communication and accessibility difficulties. (Reluctantly) asking for assistance from others has been met with greater hesitancy given the need to socially distance and avoid contact. An experience of disproportionate difference and isolation is apparent. Typically, I attempt to disarm others' responses to my visible disability by smiling and warmly interacting, hence collapsing some of the negative preconceptions the other may hold towards me. The pandemic's restrictions greatly inhibit this possibility, resulting in a loss of agency in relating as a disabled individual, producing a sense of disempowering exclusion. Fundamentally, people with dwarfism have become more disabled and disadvantaged given the contextual traumas COVID-19 brings. The paper intimately addresses how living through this pandemic uncovers several psychosocial inequalities for short-statured individuals. Drawing on critical disability and biopolitical power literature, some sense of these experiences is made. Arguably, the thoughts offered apply to people with other disabilities too, fostering greater experiential inclusivity.

12-05-2023

09:55 - 11:15 - **Health II - Disability and Health** Hilton Nordica - Meeting Room G /

- Moderator: Fredinah Namatovu, Umeå University

Inequalities in mammography screening by disability status among women across Europe

Alessandra Grotta¹, Yuvashree Ganesh¹, Can Liu¹, Mikael Rostila¹, Katja Fall², Rino Bellocco³, Ayako Hiyoshi¹

¹ *Stockholm University, Stockholm, Sweden*

² *Örebro University, Örebro, Sweden*

³ *Karolinska Institutet, Stockholm, Sweden*

People with disabilities are known to have reduced access to healthcare services, including preventative and screening services. An association between disability and diminished access to mammography screening in women has been found, mainly in the US, UK, France, Ireland and Germany. There have not yet, however, been any quantitative studies on the specific barriers faced by women with disabilities. Moreover, there is a lack of comparative international studies on the macro-level factors generating the inequalities.

Using data from the Survey of Health, Ageing and Retirement (SHARE) in Europe, we examined how inequalities in mammography screening between women with and without disabilities differ across country groups of different welfare state types, namely, the Nordic, Conservative and Southern Europe welfare regimes. Furthermore, we investigated how barriers in accessing mammograms for women with disabilities differ across welfare state types.

Using a sample of 5,687 women aged between 50 and 70, we found that women with disabilities were less likely to get a mammogram, with a North-South gradient, while the greatest differences between women with and without disabilities was observed in Southern Europe. Women with disabilities were generally more likely to report poor information and location as barriers than women without disabilities. In Southern Europe, women with disabilities also faced more obstacles in mammography screenings, including financial barriers, compared to women without disabilities.

This study highlights the important role of social welfare policies on barriers in accessing mammography screenings. Policymakers and public health professionals should be aware of the impact that disability policies can have on access to healthcare services and, ultimately, the health of people with disabilities.

The dynamic relationship between the birth of a first child and the use of disability benefits among young adults in Sweden

Fredinah Namatovu, Erling Lundevaller Häggström, Lotta Vikström

Umeå Universitet, Umeå, Sweden

Background: There is a slowly growing interest in understanding the impact of disability on the chances of having children, with a few existing studies showing that disability negatively affects one's chances of having children. However, these studies mainly examine a unidirectional relationship, we hypothesize that this relationship could be bidirectional because ascertaining relationships between variables is challenging and could be influenced by the methodology. Our study investigates whether there is a bidirectional relationship between the age of receiving disability benefits and the age of having a first child.

Methods: This longitudinal cohort study used data from national registers for people born in Sweden 1968–1970 (N=440,202). Using contingency tables and multinomial logistic regression we investigate the bidirectional relationship at different ages.

Results: Starting on disability benefits at a very early age was associated with low chances of having children during the follow-up (<42 years) period. However, people that had their first child at age 13–19 years were more likely to receive disability benefits during their 30s and 40s compared to the rest of the population.

Conclusions: This is the first study to show evidence of a bidirectional relationship between disability and parental status, also suggesting a way of addressing such relationships which is typical for data used in several fields.

Disability incidence in past society: Sweden from the 1800s until 1959

Lotta Vikström, Johan Junkka, Erling Häggström Lundevaller

Umeå University, Umeå, Sweden

BACKGROUND: While diseases have been considerably studied for past as well as present times, the knowledge about disability in history and the people concerned is poor. Contemporary studies show that disability increases with growing age affecting primarily elderly people. This study aims to identify and differentiate the disability incidence in Swedish society c. 1800–1959.

METHODS: We use data on two Swedish populations from the 1800s (N=36,500; 550 with disability) and 1900–1959 (N=194,500; 4,700 with disability) drawn from digitized parish registers. To assist national authorities to collect data on the population and its health status, the ministers reported socio-demographic information about all parishioners in these registers and on impairments perceived as disabling. This data is exceptionally rich and enables us to statistically estimate the disability incidence over time by age, gender and disability type (sensory, physical, mental).

RESULTS: Our first results suggests that the disability incidence increased from 1900–1959. In the 1950s, women had 2.6 times higher incidence than 50 years before, while it increased 2.0 times for men. The major rise started in the 1930s (Men 1.51; Women: 1.67) and grew in the 1940s (Men 1.80; Women: 2.14). Next, we will examine comparable incidences for the 1800s and distinguish between age groups and disability types.

CONCLUSION: From 1900–1959, people in Sweden experienced a consistently higher disability incidence; it doubled for men and almost tripled for women. While this increase was largely due to longer life expectancy thanks to public health improvements and since old ages tend to bring more disabilities, this increase also reflects growing concerns in society to define, or label, people by (dis)ability status, we argue.

Living Healthy Lives: Exploring the effects of growing older with cerebral palsy and use of healthcare services across the life course

Sonali Shah¹, Pip Logan², Tony Avery², Brian Bell², Janice McLaughlin³, Neil Coulson², Richard Luke²

¹ *University of Nottingham Nottingham NG7 2UH, Nottingham, United Kingdom*

² *University of Nottingham, Nottingham, United Kingdom*

³ , ,

People with CP are living longer than previously expected. However they are acquiring age-related impairments earlier than their non-disabled counterparts, brought on by physiological changes to the body as well as complex interactions between the social and biological that influence their health pathways and chances. Assumptions that CP is a childhood impairment means that appropriate health and rehabilitation support is not available to maintain the health and well-being of adults across the life course. This can lead to deterioration of mobility and functionality, loss of independence, and increase in pain and vulnerability to chronic conditions.

The Althea project is the first study in the UK to explore how adults living with CP experience ageing and subsequent secondary impairments, along with access to appropriate healthcare. It is a mixed method study funded by the National Institute for Health Research, and designed and conducted by a team of multi-disciplinary researchers at the University of Nottingham School of Medicine, Scope and a Facebook advisory panel of adults with CP.

Preliminary quantitative and qualitative results (from a national survey and life history interviews) suggest that as they age, people with CP have changing healthcare needs which must be met in order for them to maintain independence and continue being socially and economically productive. As it stands, there is a lack of understanding in adult healthcare of the impact of ageing on the physical and psychological wellbeing of adults with CP. Our preliminary data strongly suggests that there is a strong correlation between poor healthcare provision for this population and their physical and psychological deterioration as they age. It will be used as an evidence base to develop good practice.

12-05-2023

09:55 - 11:15 - **Services II / Employment - Intimate care and user involvement** Grand Hotel - Huginn /

Care recipients' management of and approaches to receiving personal and intimate care

Veronica Lövgren¹, Hildur Kalman¹, Katarina Andersson², Petra Ahnlund¹

¹ Umeå University, Umeå, Sweden

² Umeå University, Umeå,

Summary: The aim of this interview study was to explore and analyse the experiences of managing personal and intimate care among persons receiving home care services and personal assistance in Sweden (13 individuals, 25 interviews). The qualitative analysis was guided by earlier theorizing and phenomenologically informed research.

Findings: A reflected approach to the complex challenges associated with becoming and being a recipient of personal and intimate care as well as with being exposed as a person in need of support was revealed. This involved continuous adaptation and attuning to relational and organizational conditions of formal home care. The challenges further encompass adapting relationally to different care workers and personal assistants. Being a recipient of personal and intimate care does not mean being passive. It entails relating to and sustaining the care relation, where even choosing to accept suboptimal conditions is an act of agency. The recipients' private homes were hybridized: a waiting room for recipients on standby and adapted to be a workplace. The homes thus partly lost their character as a backstage realm where one could avoid the gaze of others. This led to a hybridization of the personal sphere in the form of marginal scope for true privacy, possibly necessitating strategies for protecting one's own space.

Applications: When planning and providing social care, it is important to recognize care recipients' agency, and to acknowledge the intrusive nature of personal and intimate care, which results in extensive hybridization of the home and personal sphere.

Perception of intimacy and integrity in formal home care

Petra Ahnlund, Veronica Lövgren, Katarina Andersson, Hildur Kalman

Umeå University, Umeå, Sweden

Sweden has a long tradition of providing social care and support to its citizens in their own homes through formal home care, delivered either by home care services or personal assistance. A majority of people given support by formal home care need assistance with personal and intimate care.

The aim of this interview study was on exploring care recipients', care workers', personal assistants' and care unit managers' perceptions and experiences of intimate and personal care in the context of formal home care in Sweden. In total, 57 interviews were conducted with 42 persons.

Three themes emerged in the analysis: *Personal Hygiene*, *Personal Sphere*, and *The Contextual Variability of Intimacy*. Interviewees described intimate care as being inseparable from a person's service needs as a whole. Highlighted was how caring for and washing intimate body parts, intrusion into recipients' personal spheres, and the need to preserve integrity vary depending on situational, temporal and relational aspects. To safeguard the care recipient's influence, integrity and dignity in the reception/provision of care work, home care services and personal assistance, it is important to raise awareness of the variation in perceptions of intimate and personal care in education and inhouse training.

Touch and intimacy - the body as private or public in residential institutions for intellectually disabled children and young persons?

Ingunn Fylkesnes,

NTNU, Trondheim, Norway

There is a current research interest in the topic of touch in residential settings for children. This research addresses the "no-touch-policy" following the recurrent abuse scandals in residential children's homes. This policy is now criticised, and changes occur in caring policy and practice. Research literature do mainly address conditions in child protection institutions.

Less research is carried out on how this subject is dealt with in institutions for intellectually disabled children. How do touch and intimacy appear in the everyday life in small group homes for children and young persons in need of extensive help, and who hold limited or no verbal capacity?

To explore this, I draw on observational data generated from small group homes during my doctoral research project. Empirical findings shed light on different approaches towards touch and intimacy. In accordance with existing literature, I discuss this topic considering the themes *privacy in public spheres*, *consent*, *the professional carer's institutional duties* and *ethical concerns*. The objective for this paper is among others to sign up a sparsely represented group of children, intellectually disabled children living out-of-home, for the current academic discussions.

Experience of a large and diverse sample of rehabilitation services: Issues of family involvement, age differences and gender.

Sólrun Óladóttir¹, Snæfríður Egilson², Gudrun Palmadóttir²

¹ *University of Iceland, Reykjavík, Iceland*

² ,

Purpose: To scrutinize the experience of a large and varied group of rehabilitation users of the service they receive. Emphasis was placed on the extent to which rehabilitation services in Iceland reflect the needs and preferences of users with different backgrounds and characteristics.

Materials and methods: The CCRQ-is questionnaire that measures to what extent service is user-centred was completed by 499 participants at the end of their rehabilitation period. User- centredness was measured in four dimensions, i.e., Respect and attentiveness, Responsiveness to needs and preferences, Education and enablement, and Interaction with significant others. Means of different subscales were compared with Mann-Whitney's U and Kruskal-Wallis tests to relate subscales to participants' characteristics.

Results: Overall, the subscale Respect and attentiveness represented user-centred rehabilitation the most and Interaction with significant others the least. On the Interaction with significant others a gender difference was found as women found the service to be less user centred than men. Age differences were revealed on three subscales as younger rehabilitation users found the service to be less user-centred. People with cardiac/pulmonary health issue found the service to be more user- centred on three of four subscales and those who reported mental health issues found the service to be less user centred on two subscales.

Conclusions: For all dimensions and age-groups the lowest scores were consistently found on the dimension Interaction with significant others although evidence suggests that family involvement and readiness to provide support is associated with better rehabilitation outcomes. Majority of participants reported more than one health issue. Despite that user-centred aspects appear to be almost completely separate for each field. This separation is bound to reduce opportunities for discussions about what user-centredness may in fact entail and diminish possibilities for the holistic emphasis increasingly called for in rehabilitation services.

12-05-2023

09:55 - 11:15 - **Inclusion IV - Arts** Grand Hotel - Útgarður /

Joint learning and democratic practices. Caring relationships at a day activity centre with an artistic profile

Marie-Louise Stjerna , Helen Knutes Nyqvist

Stockholm University, Stockholm, Sweden

Drawing on an interdisciplinary research arts project run by the Department of Special Education and the Department of Psychology at Stockholm University in collaboration with a Day Activity Centre (DAC) with an artistic profile we explore caring relationships within social care practices aimed for people with disabilities. Our research takes its point of departure in critical disability studies. The power dynamic of caring relationships is often imbued by ableist ideas positioning the service user as the 'vulnerable disabled Other' and the health/social care worker as the 'invulnerable expert practitioner'. Yet, there is also the potential of caring relationships to be more reciprocal offering learning opportunities for all involved. Today there is a small body of empirical studies that explore the potential of artwork in challenging the dominant idea of a dichotomy between disability and invulnerable embodiments in health/social care settings. Here we take our point of departure in an ableist approach together with a relational approach to explore caring relationships in such settings. A relational approach entails that phenomena such as learning and creative work are understood as inter-personal phenomena. This indicates that art-work produced within a DAC cannot simply be explained by individual characteristics or by the structural factors and conditions that prevail in the specific context. The relationship itself, what happens within interaction and communication processes between individuals in a particular context, is the unit of analysis. We have together with the DAC, set up a research arts project and employed ethnographic fieldwork to explore how the interaction between the staff/supervisors and the artists — adults with neuropsychiatric disabilities and adults with learning disabilities — provides opportunities for learning processes in these encounters. During our presentation we will discuss our findings; how the caring relationships offer potentials for joint learning processes and democratic practices.

On building trust: Co-producing what it means to be trustworthy through participatory arts based methods with disabled young people

Lauren White, Alison Buxton, Dan Goodley

University of Sheffield, Sheffield, United Kingdom

Trustworthy autonomous systems (or TAS) are envisaged to become part of our everyday lives. Disabled young people are key end users and potential co-designers, but they are frequently excluded from the design process and their experiences, aspirations and expertise are rarely acknowledged. In our EPSRC TAS hub funded project based in the UK entitled '[Reimagining Trustworthy Autonomous Systems with Disabled Young People](#)' we have sought to challenge this through methods of co-production and makerspaces with 8 disabled young co-researchers. One of the central conversations in the field of TAS, and indeed as part of co-production, is exploring notions of trust. In this paper, we will explore how we've approached this through arts based participatory methods and importantly, how we've co-defined, co-theorised, co-designed and co-created what it means to be trustworthy. We will do this in three ways: (1) co-producing and co-theorising trust through collectively responding to big questions such as 'What is trust?' and 'do we trust technology?'; (2) co-developing 'trust circles' to discuss technologies and their connectedness to broader relationalities and (3) how themes of co-produced, participatory, art based methodologies come through our project work with [Maker{futures}](#). Here, disabled young people are reimagined not solely as users of technologies for the future, but *trusted as makers*. Methodologically, this involved co-creating with arts based materials, working with materials together with growing relationships and trusted collaboration built along the way. Together, we hope to demonstrate how creative and participatory methods work at shaping (1) co-theorisations of trust; (2) practices and applications of trust; and (3) building trust through sustained relationships and slow collaborative work in making together. This offers methodological contributions into creative, arts based methods and co-production in disability research, as well as substantively exploring notions of trust as a relational concept for those researching technologies for the future.

Sense Art: a qualitative pilot study exploring the experiences of people with complex disabilities engaged in an inclusive arts programme

Alexandra Kaley,

Essex University, Colchester, United Kingdom

Disabled people with multisensory impairments (e.g. deafblindness) and those with complex disabilities are some of the most isolated people in society, with limited opportunities to participate and be included in their communities. Anecdotal evidence suggests that participating in an inclusive arts programme (e.g. inclusive dance workshop or arts-class – or engaging in an inclusive heritage experience) provides this group of people with opportunities to be creative, experience a greater sense of social inclusion and improves emotional and physical wellbeing. However, more robust evaluation is needed to understand how engaging in the arts benefits this group, and its potential to improve health. To-date, very few studies have sought to be inclusive of disabled people with multisensory impairments and/or complex disabilities – and more work is needed to understand how this group can be enabled to participate in research about their own lives and experiences. This paper reports on a small-scale study which piloted the use of creative and inclusive methods to explore the experiences of engaging in a participatory arts programme. Possible strategies for effectively including people with complex disabilities in future research about their experiences are also explored – which reflect new and innovative new ways of

capturing the impact and first-person experiences of art-making that reflect non-verbal, sensory, neuro-diverse and tactile contributions.

Tired of Spinning Plates? Understanding the mental health and wellbeing of carers of adults with learning disabilities

Martina Smith¹, Katherine Runswick-Cole¹, Sara Ryan², Chris Hatton², Liz Croot¹, Clare Kassa³, Rosa Cisneros⁴

¹ *The University of Sheffield, Sheffield, United Kingdom*

² *Manchester Metropolitan University, Manchester, United Kingdom*

³ *Sibs, Keighley, United Kingdom*

⁴ *Ros, Sheffield, United Kingdom*

Carers talk about the satisfaction and joy they take in their caring relationships, but they also experience many practical difficulties which can affect their mental health and wellbeing. Research shows a link between being a carer and poor mental health. Pre-pandemic, carers of adults with learning disabilities made up a quarter of the 9 million carers in the UK (DoHSC, 2020) but we know little about their mental health, their access to services and support and what they think good support looks like at different times in their lives. Recent research has also revealed the reduction in support offered to carers of adults with learning disabilities as a result of funding cuts and the challenges that carers face as they move towards retirement age. The COVID-19 pandemic has magnified the challenges faced by carers of adults with learning disabilities (Flynn et al., 2021). Despite these challenges, UK guidance on supporting adult carers continues to be limited in its consideration of the mental health of adult carers of people with learning disabilities.

In this paper we will report on emerging findings of an on-going research project: *Tired of Spinning Plates: an exploration of the mental health experiences of adults/older carers of adults with learning disabilities* (NIHR135080) which focuses on carers' mental health and wellbeing. We will report on carers' perceptions of the determinants of their mental health as well as their views on the accessibility, quality and effectiveness of support they receive. We explain the ways in which the project centralises the principles of co-production to ensure that carers are research leaders. We describe how innovative participatory approaches and a digital storytelling methodology are used to capture the carers' stories inform the development and delivery of high-quality mental health services that will meet their unique needs.

12-05-2023

09:55 - 11:15 - **Work and employment II - Employment and transition to adulthood** Hilton Nordica meeting room I /

Positive changes for young people in vocational rehabilitation: more in-company training and higher integration rates

Angela Rauch, Nancy Reims, Anton Nivorozhkin

Institute for Employment Research, Nürnberg, Germany

For young people with disabilities, a successful transition from school to working life is often difficult. Vocational rehabilitation (VR) measures support and aim to facilitate the entry into employment of PWD. To present recent developments from 2015 to 2020 and the analysis of the transition to employment, we use the VR process data panel from the Institute for Employment Research (N=34,175 entering VR in the year 2020). Persons with learning disabilities represent the largest group (40%), the share of persons with psychological disabilities (27%) is steadily increasing (persons with musculoskeletal disabilities 7%, persons with mental disabilities 19%, others 6%).

In-company vocational training often guarantees a seamless transition to working life. But only four out of ten manage to complete in-company training, though their number rises over the years. Two-third complete company-external vocational training, with declining numbers over the years.

The positive labour market trend and a constantly growing shortage of skilled workers has also led to more rehabilitants entering the labour market after completing VR (47%). For people with mental disabilities, however, the path often seems to be different: more than 90% go to sheltered workshops. People with a disability of the musculoskeletal system have the best labour market chances; eight out of ten are in employment subject to social security contributions one year after completing their training. Apprentices with learning disabilities or mental disabilities also benefit from improved transition opportunities, but not to the same extent.

At the beginning of the Corona-Pandemic employment agencies closed their facilities for several months and switched to virtual communication. Vocational psychology tests and assessments, which are necessary for access to vocational rehabilitation, were accessible only to a limited extent or on a smaller scale. Therefore, we expect less people to enter VR as well as to enter the labour market after VR.

Employment of young people with disabilities in Finland

Pauli Rautiainen¹, Karoliina Ahonen²

¹ *University of Eastern Finland , Helsinki, Finland*

² *University of Eastern Finland , Järvenpää, Finland*

Section 18 of the Finnish Constitution protects the right to work and obliges public authorities to promote employment without any discrimination. Article 27 of the CRPD provides for the right of persons with disabilities to work on equal basis with others. This is a fundamental dimension of their dignified life.

Our presentation discusses on how and why Finnish young people with disabilities face severe difficulties in accessing labour market and are to a great extent excluded from it. Exclusion starts to develop already in the education system.

Our presentation is based on interview material which we have collected as part of the research project on “Disability and Dignity” funded by the Academy of Finland. We have interviewed about forty young people with different disabilities. In these interviews, we have asked about their experiences and views on the disability pension system, working life and

disability. Based on the interviews, we have built profiles, which we use to structure the different paths of young people with disabilities into and out of working life. In our oral presentation, we will present these profiles.

Our presentation will focus on the disability pension system, which is built for securing the livelihood of people with disabilities when they have not been able to work. We will argue that the disability pension system has become arbitrary and inappropriate from the point of view of today's young people with disabilities. The disability pension system includes numerous discriminatory mechanisms, such as the treatment of blind people and wheelchair users as automatically entitled to a disability pension, regardless of their actual ability to work.

Determinants of inclusion and exclusion in the labour market - the effect of education over time

Therese Dokken¹, Jon Erik Finnvold¹, Jan Grue², Alexi Gugushvili²

¹ *Oslo Metropolitan University, Oslo, Norway*

² *University of Oslo, Oslo, Norway*

Disabled children are more likely to fall behind their non-disabled peers in educational and labour market outcomes in adulthood. The importance of education as a predictor of employment for young adults with disabilities has been well documented. Further, a growing number of studies indicate that the educational level is more important for the labour market outcomes for people with a disability. The aim of this article is to study how the level of education has affected the probability of labour market outcomes over time, and whether education has become more, or less, important in reducing labour market inequalities in Norway over the last two decades.

By using longitudinal register data, we will compare labour market outcomes for young adults growing up with a disability born from the late 1970s to the 1990s. We will compare these outcomes with the outcomes of a control group consisting of a sample of the overall population born in the same period. We will account for enabling and constraining factors, such as educational achievement, family background characteristics and social class, as well as characteristics of the municipality they were living in while growing up.

Over the study period, there has been educational reforms at all levels, from primary to higher education. Each of these reforms may have influenced the educational outcomes for both the sample of individuals with a disability as well as the control group. Levels of educational support specifically directed towards disabled people have also shifted over time, and we will consider the policy implications of our findings.

Disabled youths' experiences from transitioning to work by means of combining upper secondary school and work apprenticeships

Thea Cecilie Tvedalen, Tore Norendal Braathen

University of South-Eastern Norway, Porsgrunn, Norway

Background: People with disabilities are often excluded from the ordinary labor market in Norway. Completing upper secondary school is important for successful transitions to work,

but ordinary school programs are not tailored to facilitate disabled youths' aspirations for work. One intended exception is a four-year program combining two years of schooling with two years in a work educational apprenticeship program (WEAP).

Aim: The aim of this research was to explore how young adults with disabilities participating in a combined school and WEAP approach experienced their opportunities for choice of workplace, mastering of job tasks, and belonging.

Method: Seven students currently in or just finished with WEAP were interviewed using a semi-structured approach. The interviews were taped and transcribed and analyzed using qualitative content analysis.

Results: The students had limited opportunities to choose between workplaces for placements and apprenticeships, but still experienced some degree of choice. Those who did not have to change their original aspirations for work, reported self-efficacy concerning mastering of job tasks. The students emphasized teamwork as beneficial for inclusion in the work environment, and as important to master job tasks.

Discussion: Results from this study indicates that the degree of choice students with disabilities experience may affect self-efficacy in the transition to work, and that teamwork is a promoting factor both for mastering job tasks and feelings of belonging. To strengthen the school-WEAP combination, the schools can benefit from expanding their networks with various actors in the labor market, in order to offer students more options in their transition from school to work.

12-05-2023

09:55 - 11:15 - **Inclusion III - Inclusion in working life** Grand Hotel - Ásgarður /

The Norwegian work line – not for people with intellectual disabilities?

Hege Gjertsen,

UiT The arctic university of Norway, HARSTAD, Norway

People with intellectual disabilities are mainly excluded from ordinary workplaces in Norway. Approximately one of four adults with a known intellectual disability has a job, usually at segregated workplaces. In this presentation I will discuss how laws and regulations, as well as the practice at the Norwegian Labour and Welfare Administration (NAV) and attitudes of service providers, contribute to hamper work inclusion for people with intellectual disability. Today's practice and attitudes at NAV can be understood as a medical understanding of disability, where the reason for lack of work inclusion is related to the impairment. In addition, people with intellectual disabilities are almost automatically granted disability benefits at the age of 18. This entails a practice of a «fast-track» to segregated workplaces. This understanding of disability and practice at NAV, where people with intellectual disability are not prioritized and where segregated workplaces to a large extent are considered as the best (and only) alternative for this group, do not increase work inclusion at ordinary workplaces.

The Institute of Social Education at The Arctic University of Norway (UiT) conducted in 2018-2021 the research project "Rethinking work inclusion for people with intellectual disability",

funded by the Norwegian Research council (NRC). Collaboration partners were NTNU, HINN (Inland Norway University of Applied Sciences), USN (The university of Southeast-Norway) and the University of Iceland. This presentation is based on one of the work packages in the NRC -project, a qualitative study, and interviews with supervisors at NAV offices.

Inclusive workplaces for people with disability – a rapid literature review

Kristina Palm¹, Annika Vänje²

¹ *Karlstad university, Karlstad, Sweden*

² *Högskolan Dalarna, Borlänge, Sweden*

In Sweden, the Discrimination Act (SFS 2008:567), aims to counteract discrimination and promote equal rights and opportunities for all despite factors such as disability, sex, ethnicity, and religion. In practice, this means that work organizations need to work for diversity and inclusion. This work is often manifested through recruitment process and to ensure, for example, that gender and disability do not constitute an obstacle for employment. However, the fact that an organization achieves diversity does not automatically mean that the employees have a sense of inclusion.

Shore et al (2011, p. 1265) define inclusion as “the degree to which an employee perceives that he or she is an esteemed member of the work group through experiencing treatment that satisfies his or her needs for belongingness and uniqueness”. Inclusion in working life leads to many positive aspects such as good working relationships, job satisfaction, intention to stay, improved work performance, sense of organizational belonging and commitment, well-being, increased creativity and career opportunities (Shore et al 2011). Exclusion, on the other hand, risks leading to negative effects on psychological and physical health (Alexanderson, 2004), regardless of whether the exclusion occurs due to obvious prejudices or subtle forms of discrimination (Shore et al 2018).

The purpose of our presentation is to present a systematic overview of the research on disability and inclusion in working life and identify knowledge gaps relevant for the Swedish context. The study is conducted as a systematic literature study with literature search in international and Nordic databases. The project used predetermined inclusion and exclusion criteria and all reviewed articles in this project represent research of good standard.

Furthermore, we will present a short overview of a 3-year research project starting in January 2023, that to some extent builds on the review and aims to examine disability and remote work.

Ecological framework for conceptualizing the meanings attributed to autistics employment experience: Employees & coworkers' dyadic perspectives

Naomi Schreuer¹, Michal Waisman-Nitzan¹, Eynat Gal²

¹ *University of Haifa, Haifa, Israel*

² *University of Haifa, ,*

Background: Meaningful participation in employment is a primary concern for adults in general and for adults with autism in particular. However, adults with autism employment rate

remains low, despite proven abilities and high motivation. Research ascribes this gloomy status to complex interactions between personal and environmental characteristics. In the present research we used dyadic interviews with high functioning autistic employees and their co-workers based on an ecological framework to address two research questions: (a) what can we learn from dyadic perspectives of autistic employees and their coworkers regarding their daily work experience?; (b) what can we learn about their experiences, support and accommodations required from the workplace?

Methods: Within the phenomenological approach, we interviewed 20 dyads of autistic employees and their coworkers from Israel and Australia. Different interviewers conducted The interviews separately, by using an interview guide to cover the topics: job description, daily routine and experiences; work environment; enabling and challenging factors; supports and accommodations. The interviews were recorded and were transcribed verbatim confidentially. Interviews analysis used seven steps of dyadic analysis to delve into the experience of autistic employees nested in a workplace ecosystem, mostly to identify similarities and gaps within each dyad.

Results: We identified six subthemes: Identity as an employee versus an autistic person; Belonging to a workplace; Workplace settings; Workplace procedures; Inclusive policy; Vocational support services. Additionally, we mapped the themes based on Bone's Bioecological model (2015), which proposes good and problematic practices.

Conclusions: Presenting similarities and differences within dyads of autistic employees and their coworkers unveils risk for thoughtful friction between autistic employees and the organization. Such interaction highlights the complex environmental factors to be addressed, based on the meso level of the ecological framework: disclosure, physical and social accommodations, and job related and social communication. The study provides examples and recommendations.

'Everybody wins' – or do they? Demanding disability inclusion in the rapidly changing working life

Aarno Kauppila, Reetta Mietola

University of Helsinki, Helsinki, Finland

During past six decades the global disability rights movement has fought for inclusion – the full and complete realisation of the human rights and fundamental freedom – of disabled people to take place at all levels of society. While there have been some major shifts in focuses of the political demands, as has been well documented by earlier research focusing on the disability movement, work inclusion has sustained its place as one key focus of political action. However, at the same time as work inclusion understandably continues to be considered imperative for achieving full inclusion of disabled people, there seems to be very little discussion in this context about recent and ongoing changes in working life. This has led our research project studying disability activism and past and present of Finnish disability movement to wonder whether the image of labour market citizenship carried by demands concerning work inclusion resonates with current realities and ambivalences present in labour market participation, including precarity and unsustainability of some forms of paid labour. In addition, if 'everybody wins' through work inclusion, as a recent campaign of multiple Finnish disability organisations suggests, is this political action aiming to produce a wider change in working life, or just integration of disabled workers in this field?

By drawing from critical disability theory, sociology of work and social movement research, our paper discusses images of work and change in political action promoting work inclusion of disabled people. Our data consists of recent policy reports focusing on work inclusion, campaigns related to work inclusion and other texts produced by key actors in Finland promoting work inclusion of disabled people. Our paper asks (1) how is work defined and represented in the texts, and (2) how and whether this disability inclusion challenges and changes work?

12-05-2023

11:30 - 12:50 - **Services II / Employment - User participation** Grand Hotel - Huginn /

Professionals' experience of power in coordinated individual planning with adults who have an intellectual disability

Liv Nordström¹, Kitty Lassinantti¹, Öie Umb Carlsson², Anna-Lena Almqvist¹

¹ *Mälardalen University, Eskilstuna, Sweden*

² *Uppsala University, Uppsala, Sweden*

A person with intellectual disability often needs care and support from different organizations and professions. Coordinated individual planning is a tool for interprofessional and interorganizational coordination with the objective of creating a joint plan for a person needing cohesive care. It is based on the idea of a meeting between equal parties where everyone comes with their own part to contribute to cohesive care and support for the individual. The individual is seen as an important party and participation by the individual is considered essential for effective coordination. In this study we use a theory of power to analyze professionals' experiences of coordinated planning with adults who have an intellectual disability. We want to explore the conditions for a meeting between equal parties and how power relations can affect the work of professionals to support participation for a person with an intellectual disability. A qualitative content analysis of interviews with 17 professionals from various organizations in Sweden has been carried out with the support of Steven Luke's theory of three-dimensional power. Preliminary results will be reported at the presentation.

How do users with comorbidity perceive participation in social services? A qualitative interview study

Amanda Jones¹, Kari Jess¹, Ulla-Karin Schön²

¹ *Högskolan Dalarna, Falun, Sweden*

² *Stockholm University, Stockholm, Sweden*

How do users with comorbidity perceive participation in social services? A qualitative interview study

Background: User participation is emphasized in legislations, social care policies and codes of ethics. However, it is unclear what user participation entails and the definitions may vary

depending on whether users, politicians, or staff are asked. Moreover, it is known that users with a comorbidity of mental illness/neuropsychiatric disorders and substance use problems at times lack the opportunity to participate in decision-making processes.

Purpose: This study aimed at constructing a theoretical framework that explains how users with comorbidity of substance use and mental illness/neuropsychiatric disorders portray user participation in social work encounters.

Methods: To construct this framework a constructivist grounded theory approach was used with semi-structured qualitative interviews with 12 adult users in Sweden.

Results: The main concern of the participants was the low trust in the social services and a perception that this lack of trust is mutual. Establishing mutual trust is a social process that cuts through the whole framework and is essential in the decision-making process. In the framework, prerequisites for participation are explained. The prerequisites are users being motivated and having the willingness to stop using drugs and receiving support, making use of user and staff knowledge and decision-making abilities, and accessing help and support.

Conclusion: Unlike previous frameworks, the model describes participation as a social process instead of participation at different levels of power. The results suggest that staff need to be aware of low trust perceptions and work on establishing mutual trust. In addition, the staff need to see each user as an individual and consider how the user would prefer to be involved in decision-making.

Development of a methodology for the evaluation of services for people with disabilities

Sari Vuorilampi, Riikka Haahtela

Validia Ltd., Helsinki, Finland

Validia Ltd is a private disability service provider in Finland. Validia's goal was to obtain researched information on the use of RAI (Resident Assessment Instrument) in disability services and develop it for national use. Our aim was to assess the suitability of RAI for assessing the functional capacity and quality of life for residents in assisted living, to develop the inclusion of people with disabilities as part of the service needs assessment, and to guarantee timely and adequate services for people with disabilities based on assessment.

International RAI tools have been developed for over 25 years by the independent international network of research InterRAI. RAI includes international, standardized set of data collection and observation tools. It has been used more than 40 countries for service needs assessment and individual service planning. In Finland, RAI has rarely been used in services for people with disabilities.

Our aim was to develop an assessment method for disability services for national use in co-operation InterRAI by experimenting RAI CHA (long version) and RAI VAP (short version) in Validia's services. The pilot took place in 2022, with a total of 16 housing units and around 400 clients. The pilot resulted in a new assessment tool, RAI CHA VAP, which was validated at the end of 2022, based on a comparative study of the assessments (RAI CHA and RAI VAP).

Another key study focused on the development of service categories. A group of InterRAI researchers were responsible for developing the service categories. The method used was a

regression tree. As a result of the study, 6 groups were obtained based on four RAI indicators. The results can also be used to evaluate the necessary human resources.

Keywords: Resident Assessment Instrument, assessment, service needs

User involvement in the Nordic countries - empirical results on motives, methods, and effects

Jens Ineland,

Umeå universitet , Umeå, Sweden

User participation is part of a larger societal development and an attempt to democratize and improve welfare services, challenging the history of paternalism against people with disabilities. Many theoretical and ideological arguments for user involvement have been made and many definitions have been formulated. Some have stated that involvement from users is one of the main ingredients in efficient and effective help- and support services. Others have put forth the democratic aspects and consumer aspects of involving users. While the first aspect assumes that user participation leads to more democratic decision-making, the other advocate participation, and involvement to make various welfare sectors more efficient through consumer choice. Although many well-funded arguments exist for user involvement, there are still apparent challenges regarding how to carry out inclusive practices, implement user involvement programs, and assess and value the effects and outcomes of different programs and initiatives.

In this session, I present the main results from a recently published knowledge compilation dealing with motives, methods, and effects on user involvement in the Nordic countries with a special interest in adult citizens in socially disadvantaged living conditions, including people with disabilities. The background data is primarily Nordic research literature published between 2010 and 2022, as well as two questionnaires issued to researchers and experts in the Nordic region. The presentation provides empirical evidence to a number of questions, such as: what are the primary methods used to study user involvement in the Nordic countries? What are the main differences and similarities between the Nordic countries? What is evident in research about the effects and outcomes of user involvement strategies? What is the implication of these results for further development of user involvement in the Nordic countries?

12-05-2023

11:30 - 12:50 - **Work and employment II - Employers' perspectives**

Hilton Nordica meeting room I /

Employment of danish flex job workers – an employer's perspective

Emilie Skyum-Jensen,

Aalborg University, Copenhagen, Denmark

What make employers hire a person with a disability in a flex job?

In this presentation I will present the findings from my master's in social work thesis, which will be written in collaboration with Research Center for Disability and Employment at Center for Labour Market Research, Aalborg University. The aim of the thesis is to examine employers' engagement and experiences with a focus on successful flex job recruitment processes. The danish flex job program is an active labour market program introduced so more people with reduced working capacity (including people with disabilities) would be integrated into the labour market. A flex job is a part time job, where the worker receives a wage subsidy from the public job centers and a salary from the employer.

The thesis will be based upon interviews with danish employers who have experience in employing people with disabilities in flex jobs and where the employment has turned out successfully. The study is therefore based upon a best-case design. I want to examine employer engagement in relation to the employment of flex job workers: when and why do they employ a flex job worker? Why was this a successful job match? What are important components in a successful flex job employment according to the employers?

Employers play a decisive role in relation to the integration of people with disabilities into the labour market and in relation to the employment situation of people with disabilities in general. Employment is the first step towards integration, and therefore it is important to examine which components engage employers. Despite employer's decisive role, employer engagement and experiences have only been studied to a limited extent. An employer's perspective can therefore offer valuable knowledge about "what works" when people with disabilities are to be employed into the "ordinary" labour market.

How frontline workers strive to challenge public and structural stigma towards disability when encouraging employer engagement.

Camilla Stub Lundberg, Per Koren Solvang

Oslo Metropolitan University , Oslo, Norway

The engagement of employers is critical to work inclusion policies, yet limited is known of how frontline workers implementing these policies interact with employers. This paper examines the stories of frontline workers in the Norwegian labour and welfare administration regarding employer engagement in terms of the willingness of employers to recruit and hire disabled people. Based on interviews with frontline workers, the study unpacks how they face a difficult situation in their engagement: not only must they continuously deal with the stigma associated with disability, but they must also manage employers' negative impressions of the welfare service as a supplier of less-than-ideal employees whilst adhering to policy demands for commitment to ordinary paid work. The concepts of public and structural stigma are applied. They highlight that disability is devalued and that institutions and ideologies can preserve stigma. These concepts help analyse frontline workers' efforts employing three strategies: 1) Frontline workers attempt to reduce stigma by comparing disability to other less stigmatised groups without employment, a comparison that is illustrated with portrayals of employers' negative associations with welfare services. 2) They also focus on the citizens' competences and resources before disclosing disability. 3) Lacking the opportunities of modifying a barrier-prone working life are also brought up, indicative of the constraints of frontline workers' employer engagement. In a final section, this paper raises implications for policy and practice by addressing possibilities of challenging public and structural stigma.

Work inclusion for people with intellectual disability (ID) –employers' perspectives

Lisbeth Kvam, Patrick Kermit, Aud Elisabeth Witsø,

Norwegian University of Technology and Science, Trondheim, Norway

Introduction: Despite positive attitudes among many employers, as well as an increasing number of initiatives promoting work inclusion, people with ID remain largely excluded from the labor market. This presentation stems from a qualitative study that followed up a survey among 1480 employers measuring attitudes towards hiring employees with ID, as well as the influence of enterprise characteristics on these attitudes.

Aim: The aim of the study was to enhance knowledge on employers' understandings of ID in terms of social, executive, and work-related developmental capacities. Moreover, it sought to capture employers' thoughts concerning the workplaces' ability to hire and adapt work tasks, needs for external support, and general strategies that contribute to the employment of people with ID within their field.

Methods: Nine employers, recruited through the survey, were interviewed. Two different semi structured interview guides were developed; one for employers who had experience from hiring workers with ID, and one for employers who did not have this experience. Thematic analysis was conducted on the interview transcripts.

Preliminary findings: So far, the overall findings seem to indicate that the employers considered individual traits such as cognitive abilities, appearance, and social competence as attributes that may either complicate or facilitate ordinary employment for people with ID. Furthermore, the employers had different, or even conflicting, understandings of the work ability of employees with ID. A major concern seems to be that employers with ID were perceived as vulnerable, especially when confronted with unforeseen situations and in mastering work tasks. Finally, the employers experienced that while external supportive measures were necessary, they could also be challenging for the workplace.

Exploring Disability Disadvantage in Hiring: A Factorial Survey among Norwegian Employers

Stine Berre,

Norwegian University of Science and Technology, Trondheim, Norway

Disabled people continue to have a marginalised position in labour markets across the globe, with their employment levels falling far below those of non-disabled. Although the reasons behind this continued employment gap are complex and multifaceted, the important role of the demand-side has increasingly gained attention in the literature. Studies on employer discrimination and hiring attitudes show that employer reluctance towards hiring people with disabilities represents significant barriers towards this group's equal access to employment.

This paper further explores disability disadvantage in employers' hiring assessments using a factorial survey analysis (FSA). The FSA allows for a multidimensional approach to the study of employer attitudes, where several characteristics of the job seeker can be investigated simultaneously. In this study, fictive non-disabled and disabled job seeker candidates were evaluated by a random sample of Norwegian employers (n=1,341), on a scale from 0 (hiring

"highly unlikely") to 10 (hiring "highly likely"). Several job seeker characteristics believed to impact the employers' judgements were simultaneously manipulated. Multilevel linear regression analyses were performed, to analyse how a) the presence and type of disability, b) information about publicly financed support measures, and c) other individual characteristics of the job seeker impacted employers' hiring assessments.

The results reveal that adding information about any type of disability to the job-seeker profiles causes a significant decrease in the likelihood of employers wanting to hire a candidate. The degree of disadvantage varies with the type of disability and the presence and type of public support measure. This study also finds that when disability is introduced to a job-seeker profile, other crucial characteristics of the job seeker lose some or all of their impact on employers' assessment scores. This is interpreted as disability becoming a 'master status' when employers are faced with making hiring assessments.

12-05-2023

11:30 - 12:50 - **Inclusion III - Inclusion in adulthood** Grand Hotel -
Ásgarður /

„Even the way I make my coffee is autistic“: The experiences of autism by late-diagnosed Icelandic women

Kremena Nikolova-Fontaine, Snæfríður Þóra Egilson

University of Iceland, Reykjavík, Iceland

The aim of this qualitative interview study was to shed light on late-diagnosed autistic women's life experiences prior to their diagnosis, and the meaning-making of their diagnosis on their lives and identity. The study was informed by the lens of critical disability studies and critical autism studies. Five mature women who all had shared their experiences in a documentary about autistic women participated. The Interpretative Phenomenological Analysis (IPA) was used in data analysis. In retrospect, the women described painful experiences from their youth and their struggles with meeting the demands of typical social and work environments due to their autistic characteristics and inaccessible environments. Thus, personal and environmental dimensions uniquely interacted to mediate the women's exclusion. The women's late diagnosis made them revise and rewrite their past, emphasizing environmental aspects instead of assuming personal blame for the hardship they had endured.

Masking ADHD, Autism, and Dyslexia: Burnout in Neurodiverse Individuals

Summer West,

Universität Kassel, Kassel, Germany

What is masking in neurodiverse individuals, and how does it result in burnout? Masking refers to the suppressing of certain innate behaviors for the purpose of appearing less different from those in one's environment. While masking can facilitate success and high achievement among neurodiverse individuals, it is accompanied by significant anxiety that

results in burnout, which can then induce additional mental health disorders and medical conditions. ADHD, autism, and dyslexia are all included in the neurodiversity paradigm and have been reframed as phenotypes rather than disabilities among advocates for neurodiversity recognition. All three have been associated with elevated burnout, yet not all three receive equal treatment in the literature on masking. This presentation will address three themes that have materialized in a thematic analysis of relevant literature combined with socio-cultural discourse that centers varied personal narratives on the lived experience of neurodiversity. First, masking is generally attended to within the autism spectrum while less attention is paid to ADHD and dyslexia, though the impact of burnout is no less severe among individuals who mask their ADHD or dyslexia. Second, high rates of co-occurrence for ADHD, autism, and dyslexia alongside a diagnostic overshadowing of one over another may hinder attempts of counselors and disability service providers to circumvent the burnout associated with masking. Third, underdiagnosis of ADHD, autism, and dyslexia in the general population remains a consistent issue across cultures and must be examined through a better understanding of masking within the context of the neurodiversity paradigm.

Transition to employment and post-secondary education of young adults with IDD: Voices from Minnesota

Renata Ticha, Brian Abery,

University of Minnesota, Minneapolis, United States

This presentation is based on a Minnesota Project of National Significance (PNS) funded by the Administration on Community Living (ACL) titled *Community-Based Collaborative Transition Model for Minnesota Youth with IDD*. The purpose of the project is to improve transition outcomes of youth and young adults with IDD to employment and post-secondary education, and independent living. The project is conducted in partnership with Minnesota Department of Employment and Economic Development, Department of Education, Department of Human Services, four transition programs/initiatives, employment and advocacy agencies, and Utah State University. In Minnesota, there is a synergy between a state-level transition initiative, the Transition Toolkit, launched this year, including a state transition framework. It is in this context we have conducted Landscape Analysis to map the experiences of youth with IDD, their family members, educators and support staff with the transition structures and processes. As part of the Landscape Analysis, we conducted site visits, interviews and photo elicitation with youth with IDD as well as focus groups with family members, educators, and support staff in four transition programs/initiatives in Minnesota. The data were analyzed qualitatively using case studies and thematic analysis (grounded theory) to build a map of experiences with transition in Minnesota. The site visits, interview, photo elicitation and focus groups results revealed several themes. Transition has different meanings for youth with IDD. There are limited opportunities for youth to experience integrated & competitive employment, largely dependent on the location, transportation availability, and on the creativity of work-based learning coordinators and staff. While there are currently more options for employment in the community, there is hesitancy on the part of employers to take youth with IDD into higher-paying positions. Typical work-based opportunities include cleaning, assembly, packing, and stocking. There are differences between transition programs/initiative regarding paid vs. volunteer work opportunities.

How strength-based leadership facilitates working ability – shedding light on the role of disability types

Nicola Glumann¹, Magdalena Schertler¹, Aileen Schloemer-Jarvis², Stephan Alexander Boehm¹

¹ *University of St. Gallen, St. Gallen, Switzerland*

² *Leuphana University Lüneburg, Lüneburg, Germany*

People with disabilities make up a significant portion of the workforce and empirical evidence showed that employees with disabilities experience some aspects of their work more negatively than employees without disabilities (e.g., employees with disabilities reported lower level of perceived inclusion within their work group; Dwertmann & Boehm, 2016; Villanueva-Flore et al., 2017). Even though disabilities are very heterogeneous and it seems inadequate to look at employees with disabilities as one homogeneous group, to date, only few studies have directly compared different types of disabilities (e.g., Hipes et al., 2016; Synder et al., 2010). The aim of our study is to look at leadership as one of the main levers for promoting employees' perceived inclusion (e.g., Ding & Yu, 2021) and working ability (e.g., Ding & Yu, 2022; Soderbacka et al., 2020), while investigating differences in the effects of leadership in employees with different types of disabilities. Given that disability is often associated with deficits (e.g., McLaughlin et al., 2004; Nota et al., 2014), we propose that *strength-based* leadership could be particularly relevant for supporting employees with disabilities. Therefore, we contribute to the field by analyzing the influence of strength-based leadership on working ability, possible mediation by inclusion and moderation by disability type in a moderated-mediation model. Using data from an online survey, questioning $n = 3246$ Swiss employees, including employees with *physical*, *sensory* and *psychological* disabilities, we were able to confirm the moderation by disability type: Only in employees with *physical* disabilities, strength-based leadership has a more positive effect on inclusion. Regarding working ability, employees without disabilities show a more positive effect only in comparison to employees with *psychological* disabilities. Both results demonstrate the necessity to distinguish between disability types to support employees working ability in the best way possible.

12-05-2023

11:30 - 12:50 - **Disability and the lifecourse II - Policy** Hilton Nordica meeting room H /

From 5 to 25 years of age - an age cohort with Downs syndrome growing up in Norway

Anne-Stine Dolva,

Inland Norway University of Applied sciences, Lillehammer, Norway

A first generation with Downs syndrome has grown up within the frames of Norwegian disability policy based on normalisation, inclusive schooling and the right to participate in society on equal conditions. Scarce knowledge exists on what characterises the period in life from school entry to emerging adulthood for a same-age group of individuals with Downs syndrome.

The research questions are: 1) What characterises the course of life from 5 to 25 for an age cohort with Downs syndrome? How can this course be understood within the national disability policy of this period, and what are barriers and possibilities for inclusion and participation?

The study will draw upon results from a project following a Norwegian age cohort with Down syndrome for 20 years in different studies. The age cohort counts 43 individuals out of a cohort of 62 born children. Studies has been conducted at their age of 5, 7, 10, 14, 17, 22 og 25. Focus has been on school entry, capability development, the entire course of education, peer interaction, folk high school, leisure activity, friendship, emerging adulthood, work, housing, and quality of life. Informants of some studies were parents while the emerging adults themselves were informants in the last three studies.

Results from eight international and six national publications will be analysed in order to describe the life course of these individuals. It is both qualitative and quantitative publications.

The life course characteristics will be discussed with the frames of the Norwegian disability policy. Moreover, inclusion and participation barriers and possibilities will be discussed with theory that integrates the concepts *quality of life* and *supports*.

Changing and new mechanisms of societal marginalization of disabled people in post-socialist Hungary

Gabor Petri, Agnes Turnpenny, Aniko Bernat

TÁRKI Research Institute, Budapest, Hungary

Hungary, in common with most post-socialist countries, has enacted a number of human rights-driven laws and programmes since the 1990s, including legislation on accessibility, non-discrimination, long-term care, and legal capacity. Consequent national disability action plans have also aimed to facilitate progress for over 20 years. Yet, this progress is hardly featured in civil society organisations' and shadow reports to the UN CRPD that regularly highlight serious problems in both policy and implementation.

Our study explores how decades of legal and policy changes are reflected in the lived experiences of disabled people and aims to identify old and new mechanisms of marginalisation; factors that cause or exacerbate the social exclusion of disabled people in Hungary. Our mixed-method approach included

a representative survey about social attitudes about the rights of disabled people;

critical policy analysis of social and disability policies;

life-course interviews with disabled people and family members;

focus groups with disabled people, carers, and disability rights activists;

media analysis about media representations of disability in contemporary media discourses.

In our presentation we present core findings of the research. Policy analysis showed that still only a fraction of disabled people access social services that support independent living, and residential institutions are still a dominant form of social service. Life course interviews with 93 disabled people featured serious and systemic barriers to independent living that remain often unchanged even during and after 'progressive' legal changes. Our media analysis found that Hungarian contemporary media dominantly report on disabled people as victims or as beneficiaries of support and users of services. Certain disability groups such as people with an intellectual disability and autistic people are the least visible of all disabled people in media. We will also reflect on participatory research approaches employed in our project.

Accumulation and intergenerational transmission of disability – What are the consequences?

Anna Amilon, Rikke Fuglsang Olsen, Stine Vernstrøm Østergaard

VIVE the Danish National Center for Soci, Copenhagen, Denmark

Objective

To investigate if growing up with parents and / or siblings with a disability influences socio-economic outcomes in adulthood.

Background

Although it is well established that health and socioeconomic disadvantages often accumulate within families, little is known about the extent to which disability accumulates within families and whether accumulation of disability within the family in childhood shapes opportunities and outcomes later in life.

Method

This study uses data from the 2020-wave of the *Survey of Health, Impairment and Living Conditions in Denmark* (SHILD) to examine the association between childhood accumulation of disability (i.e., whether growing up with parents and / or siblings with a disability) is linked to own disability, the probability of having dropped out of an education, family status and loneliness later in life.

Results

Parents' and siblings' disability is positively associated with own disability. Moreover, when controlling for own disability, parents' and siblings' disability is positively associated with having ever dropped out of an education, loneliness and having a child with a disability.

Conclusion

Disability accumulates within families, is transferred across generations and influences the next generation's socio-economic outcomes negatively. Thus, even in a comprehensive welfare state like Denmark, families with disabilities need more support in order to break intergenerational cycles of disadvantage and to reduce health and social disparities between individuals with and without disabilities.

Bridges over barriers – concepts and policies at the intersection of disability and old age

Salla Era,

University of Jyväskylä, Jyväskylä 40014, Finland

In this presentation, I aim to discuss the themes of my dissertation that focuses on the intersection of ageing and disability from the viewpoint of concepts and policies. Within many countries, the policies on disability and old age have been developing on distinct paths, including Finland. Even though the prevalence of disability is higher in older populations, older persons tend to be excluded from disability discourses. The aim of this dissertation is to help build bridges between research and policies of the respective fields of ageing and disability. My research participates both theoretically and conceptually in developing the research field at the intersection of disability and old age. In my dissertation, I ask 1) what the nexus of old age and disability is like in the Finnish service system, 2) what kind of understandings and conceptualisations are found in this intersection, and 3) what kind of experiences do older persons with disabilities have of the service system and getting old more generally. The data of my dissertation consists of policy documents, international research (systematic literature review) and letters received by invitation to write (n = 24) from older persons with disabilities. The findings suggest that disabilities associated with ageing are not always seen as disabilities *per se*, and the origin of the impairment often determines the course of action within the service system. Equality is used to justify both the inclusion and exclusion of age-associated disabilities, depending on the perception of disability. There is conceptual confusion at the intersection of ageing and disability, and there does not appear to be a consensus in research or policies as to what disability is.

12-05-2023

**11:30 - 12:50 - Human rights II - Disability and violence:
Phenomenon and violence experienced by persons with disabilities**
Grand Hotel - Hvammur /

- Moderator: Minna Liisa Luoma, Finnish institute for health and welfare

Domestic violence experienced by persons with disabilities: Results of the Disability and Domestic Violence survey (2022)

Anna Väre, Minna Liisa Luoma, Maria Valtokari

Finnish institute for health and welfare, Helsinki, Finland

Aim: Research has repeatedly demonstrated that people with disabilities, experience violence at higher rates compared to people without disabilities. The aim of the survey was to find out different types of violence are experienced by people with disabilities and the experiences of seeking for help and receiving it.

Methods: This survey was broadly marketed in social media and by different disability societies. The results were analyzed using descriptive statistics. There were 170 respondents.

Results: 58 % of the respondents were 18 to 49 years old. 91 % were living in an apartment of their own and in city or suburban settings (81 %). Most of the respondents (n=149, 70 %) had experienced violence in one or more of its forms in the past. Majority (91 %) had experienced 2 or more different forms of violence. The most common perpetrators were former or current spouses or other close persons. Some had experienced violence or maltreatment by health or social care professionals. Violence had negative effects such as feelings of hopelessness, shame, fear and depression. Many had experienced pain, bruises and/or economic difficulties. Most of the respondents had told about violence to someone (72 %). Many respondents (37-45 %) had not received help from an official party when they had requested it. Many felt that help was not enough unobstructed (44 %), accessible (47-33 %) or easily available (60-63 %).

Conclusions: A lot of work is yet to be done in the recognition of violence and maltreatment of persons with disabilities among officials (police and social and healthcare professionals). The help for survivors should be enough long-lasting, easily accessible, and available and unobstructed. It is important to acknowledge that the perpetrator is often someone close for person. More research is needed on this phenomena especially among people with disabilities living in institutionalized settings.

Domestic violence experienced by persons with disabilities: Results of the Qualitative interviews

Maria Valtokari, Anna Väre, Minna Liisa Luoma

Finnish institute for health and welfare, Helsinki, Finland

Background: There were 13 interviewees (n=13) who identified themselves as persons with disabilities and experiences of domestic violence (DV). The interviews were conducted in autumn 2021. The interviewees were adults of both genders. They had the option to utilise a personal assistant or another trustworthy person in interviews, for example, to help with computer or translate speech to sign language.

Aim: The aim of the interviews was to gather information of interviewees experiences of domestic violence, consequences of DV, seeking help and finally thoughts about the future.

Methods: Interviewees were recruited by using the snowball-sampling method. The qualitative, semi-structured thematic interviews were analysed inductively by thematic analysis (and the codings and groupings were analysed by using Atlas.ti 9). Interviews were conducted in Microsoft Teams, however they were recorded separately via a dictation machine.

Results: DV experienced by persons with disabilities is a multidimensional phenomenon. Interviewees described seeking help and things which hindered getting help. Interviewees also described different ways of coping with DV. The consequences of DV were the following: depression, anxiety, anger, sorrow and fear.

Conclusions: The results of these interviews are useful for educating professionals and persons with disabilities. These results also indicate that social and healthcare services do not recognise DV as the multidimensional phenomenon that it is. During the administration of services, professionals should ask about DV or just simply ask regularly "How are things at home?" By doing this, the professional can get information about DV. This could also be useful for seeking help. People with disabilities are quite often dependent on a violent

person. It should be taken into consideration that a violent person can prevent a person with disabilities from getting access to help.

Preview about the Finnish study: Domestic violence experienced by persons with disabilities

Minna-Liisa Luoma,

Finnish institute for health and welfare, Helsinki, Finland

Aim: The aim of this study was to investigate the frequency of domestic violence experienced by persons with disabilities and the factors related to it. The outcomes of the project will be used to take the phenomenon of domestic violence and its frequency into account and to issue recommendations for measures.

Methods: The research data used in the study include population study data sets, which are the School Health Promotion study (2019, 2021), National FinSote Surveys (2018, 2020) and the FinHealth 2017 follow-up study (2020). In addition, the Disability and Domestic Violence survey and interview data collected in the project (2021) was used as research data. For this study there were approved decision from the Ethics committee of Finnish institute for health and welfare.

Results: Domestic violence is more common for persons with disabilities than in the rest of the population. There are differences between genders in the frequency of experiencing different forms of violence. Violence experienced by persons with disabilities may start in childhood, and it is more common among them up to adulthood. Domestic violence may especially cause psychological consequences for those who have experienced it. Successfully acquiring help for domestic violence may depend on the disability, the people close to the person and the circumstances. There are major challenges associated with acquiring help, and these challenges deserve attention and require taking measures to improve the situation.

Conclusions/recommendations: Improving the situation of persons with disabilities who have experienced domestic violence in our society begins by identifying the phenomenon, its diversity and persons who experience it.

12-05-2023

11:30 - 12:50 - **Childhood disability III - Services and support** Hilton Nordica meeting room F /

Children's participation in the process of assessing the need for support according to the Swedish Disability Act

Elisabet Björquist, Martin Molin, Stina Persson

University West, Trollhättan, Sweden

For several years it has been emphasized that the children's perspective should be strengthened in Swedish disability legislation. However, recent studies show that children with disabilities are lacking participation in the assessment process i.e., in decision-making and planning for support, in accordance with the Swedish Disability Act (LSS). Social workers who investigate children's needs should not only have knowledge of assessment and regulations, planning, decision-making, and follow-up of individual support, but also have knowledge of disability and its consequences. Further, they should be skilled in talking with and relating to children, which includes communicating with children with limited communication skills. However, it has been shown that social workers display a reliance on parents' descriptions of their children's needs, which indicates a lack of knowledge and tools for direct communication with children who have limited resources to communicate verbally. In this project presentation will examine, from professionals, children's and their parents' perspectives, how increased participation can be made possible for children with disabilities during the process of decision-making and planning for support. How do social workers, children with disabilities, and their parents describe opportunities or obstacles using Augmentative and Alternative Communication (AAC) and digital technology during the assessment process? How do children with disabilities and their parents experience the meeting with the social workers regarding the child's participation during the process of decision-making and planning and for support? Empirical material has been gathered through qualitative individual and focus group interviews with social workers (n=28), children with disabilities (n=11), and their parents (n=12). Children were interviewed using the method 'Talking Mats'. We adopted a thematic analysis model, and the themes has been analysed with Shier's model of participation. Preliminary results will be presented and implications for research and practice will be discussed.

Crisis response for refugee children with disabilities

Jamie Bolling,

Independent Living Institute, Farsta, Sweden

This presentation will highlight the area of crisis response for refugee children with disabilities and of integration based on work that was and is carried out in Sweden through the Disabled Refugees Welcome project since 2017 and a chapter in a Routledge book coming soon. There are assumptions that children and disabled persons are not among those coming ashore in Europe, leaving governments unprepared for the reception. Through meetings with refugees with disabilities who came to Sweden during the refugee influx of 2015, the Independent Living Institute heard stories on how refugee children with disabilities are met with inaccessibility, poor treatment, prejudice, lack of support and more. They should instead be accessing their rights of self-determination and participation with their best interests taken into consideration. Refugee children with disabilities lack information that may lead to a lack of agency and empowerment, with their voices not being heard. Some of the conclusions drawn from the DRW project are that there is a gap and need for actors within the area of disability and migration to have competences in both these areas. The disability perspective, intersectional perspective, health perspective and rights perspective need to be applied when working in the field of crisis management concerning migration and integration. Another conclusion is all organisations should contribute to a paradigm shift in the humanitarian response, going from paternalism to one of empowerment and the right to participation of refugee children. The aim of the presentation is to spread the lessons learned through Disabled Refugees Welcome to help avoid the unpreparedness in the response to

the situation of refugee children with disabilities. It is also hoped that it will facilitate the safeguarding of the protection of refugee children with disabilities through participation and empowerment.

Dialogical model for enabling disabled children to influence their life

Johanna Olli,

University of Turku, Turku, Finland

Disabled children's right to influence all matters affecting the child is compromised too often, especially when a child does not communicate verbally. Influencing means their perspectives being heard and considered, not necessarily always getting what they want. Professionals in health care are often in position to guide adults around the child either towards listening to the child or acting as experts whose knowledge is more important than the child's knowledge.

By combining findings of four sub-studies and previous literature, I have created a dialogical model for enabling disabled children to influence their life through encounters with adults. Data of sub-studies consists of videotaped observations of nurses' and young disabled children's interaction in children's neurological wards. Applied conversation analysis enabled reaching for the perspectives of children who expressed themselves with nonverbal communication. The theoretical framework combines medical and social model of disability and emphasizes importance of seeing children simultaneously as "human beings" and as "human becomings". Concrete means for enabling disabled children to influence all matters affecting the child consists of respecting the child as the main character of his/her life and services, of dialogical ways of interaction and the working cultures and institutional structures which support the child's possibilities to be heard. Dialogical ways of adult-child interaction require adults' respecting the child's perspective, enabling the reciprocity and being present and using creativity.

The experiences of personal assistance in the everyday lives of disabled children, youth, and their parents

Johanna Korkeamäki,

University of Eastern Finland, Helsinki, Finland

Personal assistance (PA) is a support service that promotes choice, independence, and social participation. UNCRPD requires states to ensure that persons with disabilities have access to personal assistance, along with a range of support services. However, there seems to be a gap between national policy ideals and practical realities.

The study investigates the lived experiences of disabled children and youth who need personal assistance. In addition, the experiences of parents are studied. The study asks how personal assistance relates to experiences of agency, autonomy, social inclusion, and dignity. The data consists of individual, pair, and focus group interviews with children and youth with disabilities along with their parents.

The preliminary results of the analysis illustrate both positive and negative experiences in receiving personal assistance. The scarcity of personal assistance limits possibilities of

choice and independence especially compared to possibilities for children and youth in general. The results are discussed in relation to the capability approach and the sociological insights into dignity.

The study is a part of the Disability and Dignity project of the University of Eastern Finland (UEF). In the project disability and dignity are approached with multidisciplinary lenses in the different phases of the life course. The project is funded by the Academy of Finland [304602].

12-05-2023

11:30 - 12:50 - **Policy and theoretical perspectives V - Supported everyday citizenship** Grand Hotel - Gullteigur B /

- Moderator: Ruth Bartlett, VID Specialised University

Introducing the idea of 'Supported Everyday Citizenship'

Ruth Bartlett, Inger Marie Lid

VID Specialised University , Oslo, Norway

In this presentation, we offer the idea of supported everyday citizenship to widen discourse in citizenship and disability studies to include persons living with intellectual disability and/or dementia. Supported everyday citizenship is defined as a relational concept for enhancing the participation of persons with disabilities in need of welfare services. The idea can be traced back to five existing bodies of existing knowledge. These are (1) supported decision making (2) sociology of the everyday (3) lived citizenship (4) inclusive citizenship and (5) human rights. Supported everyday citizenship is offered as a unifying perspective and lens through which to understand the real-life circumstances of persons with an intellectual disability and/or dementia. As such, the presentation provides the theoretical context for this session on supported everyday citizenship.

Familial experiences of supported decision-making with their adult children who have intellectual disabilities and live in municipal housing: An interview study conducted in Norway.

Sadeta Demic,

VID Specialised University , Oslo, Norway

The UN Convention on the Rights of Persons with Disabilities (CRPD) refers to the right of all people to receive the support they need to exercise legal capacity (Article 12.3). Legal capacity is exercisable regardless of disabilities; all people have the right to make choices that concern themselves and to have these rights recognized by others (UN, 2006). Norway ratified the CRPD in 2013 and is therefore obligated to ensure that the rights of persons with disabilities are respected and fulfilled in line with the Convention. Supported decision-making

is key to ensuring people receive the support they need to exercise legal capacity. Supported decision-making is defined as "any process that enables the person to make their own decisions and/or to express their own will and preferences" (The Directorate of Health, 2021, p. 23). Unfortunately, knowledge of families' experiences of supported decision-making, and how practices unfold in municipality housings together with adults with an intellectual disability is scarce. More research within a Norwegian context would provide much needed evidence on implementation of the CRPD.

The study explores family members' understandings and experiences of supported decision-making practices and essential factors for decision support in relation to people with developmental disabilities who live in municipal housing.

The research questions are: What experiences do relatives of people with developmental disabilities have with decision support? What kind of dilemmas are expressed in decision-support work? What are essential factors in the decision support work seen from the next of kin's perspective? What inhibits and promotes good decision support practices, seen from the next of kin's perspective?

Individual interviews with eleven family members were conducted. In this presentation initial analysis of the family members, experiences will be elaborated on and discussed.

Long-term Care Homes: Carceral spaces in times of crisis or perpetually?

Ana Koncul , Ruth Bartlett

VID Specialised University , Oslo, Norway

The COVID-19 pandemic heightened public awareness of the realities and lived experiences of older people with dementia living in residential long-term care (LTC). While LTC is assumed as necessary and acceptable for older people with dementia in Western countries, the pandemic brought concerns about their institutional and custodial nature to the fore. This presentation explores whether isolation and control observed during COVID-19 are a pandemic effect or a perpetual socio-spatial feature of long-term care (LTC) culture. We use narrative analysis to foreground the experiences of two women with dementia trying to leave LTC: one before and the other during the pandemic. Using the lens of affective citizenship, we argue that the spatial experiences of confinement for people living in LTC are routinely overlooked in popular discourse. We reflect upon how the segregation of older people with dementia in LTC contributes to discriminatory practices beyond these institutions and advocate for a policy of deinstitutionalization.

Higher education program in human rights for students with intellectual disabilities in Norway

Anna Chalachanová,

VID Specialised University, Oslo, Norway

In practice, people with intellectual disabilities do not currently have access to higher education in Norway (NOU 2016: 17, see NOU 2016: 17, Section 8.2.6 *Higher education*). This is even though the UN Convention on the Rights of Persons with Disabilities (CRPD), Article 24 (5) states that '*States Parties shall ensure that persons with disabilities are able to*

access general tertiary education, vocational training, adult education, and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.' Norway signed the convention in 2007 and ratified it in 2013. The Norwegian Official Report *På lik linje* (on an equal footing) includes a recommendation to initiate pilot schemes for a specially adapted educational program at universities or colleges for people with intellectual disabilities (NOU 2016: 17 20.3.5). By creating a study programme at VID Specialized University that is aimed at a small group of students with intellectual disabilities, the presented project aims to highlight how access to higher education is a universal right.

Higher education in all its forms is an important arena for ensuring personal development and for qualifying people to participate in the labor market. For many, their student years are a formative period in their life. In addition to acquiring knowledge, they also form essential relationships, gain independence, and have room to grow in a less restrictive learning situation than previously.

This presentation discusses the processes linked to establishing a new educational program for students with intellectual disabilities. We emphasize participation processes and how collaboration with potential students is realized and arranged during the development of the program. We also want to present challenges linked to establishing a new educational program and experiences with the provision of the program so far.

12-05-2023

11:30 - 12:50 - **Childhood disability II - Children and their families**
Hilton Nordica meeting room D /

What challenges and support do Nepali mothers of children with intellectual disabilities encounter? A qualitative exploration

Namrata Pradhan,

Norwegian University of science and technology, Trondheim, Norway

Children with intellectual disabilities can require lifelong care representing tremendous financial, spiritual, health and social impacts for their caregivers. For mothers in low-income countries this burden may be especially amplifying; to date, in Nepal, children with intellectual disability and their family caregivers are marginal or non-existent in public health scholarship. Therefore, this study explores the day-to-day caregiving realities of Nepali mothers of these children –including their everyday experiences, belief systems, worries, fears, material and spiritual burdens, and coping strategies. In collaboration with local disability organisations, 14 mothers of children with intellectual disabilities were recruited for individual interviews conducted in 2021. A descriptive thematic analysis was carried out, revealing that the mothers perform critical roles and responsibilities in the care of these children without access to any formal caregiving support. The mothers experienced this responsibility as diverse psychological and physical stresses, social restrictions, and financial burdens, accompanied by shame, anger, frustration, and guilt affecting their mental well-being and quality of life. The mothers utilized sources of support, spiritual beliefs, coping, and hope to accept and adapt to their caregiving realities. This study provides vital

knowledge to address the needs and promote the health of families affected by intellectual disability.

An exploratory study of natural support experiences of children with intellectual disabilities and their families in Ireland

Concepta Carty,

Trinity College, Dublin, Dublin, Ireland

Children with intellectual disabilities and their families are believed to enjoy less natural support (support gained from personal associations and relationships) than those without an intellectual disability (Browne, 2013). Natural supports are typically offered by family members, parents being the main providers, followed by siblings and grandparents (Dolan, Canavan & Pinkerton, 2006; Miller, Buys, & Woodbridge, 2012; Sanderson, Burke, Urbano, Arnold, & Hodapp, 2019), and, to a lesser extent by extended family, with whom children with intellectual disabilities have fewer opportunities to engage (Shakila, Kirsty, & Santoshi, 2020).

Research on the collective natural support experiences of children with intellectual disabilities and family is scant, with parents' perspectives being most available and the wider family experience under-explored, leaving a gap in the literature (Arnold, Heller, & Kramer, 2012; Woodbridge, Buys, & Miller, 2009). Therefore, the aim of this study is to examine the natural supports children with intellectual disabilities and their families have with a focus on the experiences of children with intellectual disabilities, their primary caregivers and other family members.

This presentation will provide a review of key findings from the literature informing the study, an introduction to Bronfenbrenner's ecological systems theory and family systems theory framing the study, and an explanation of the qualitative case study approach adopted with a minimum sample of 15 families including the child, one primary caregiver and a member of the wider family circle, employing an IPA approach that facilitates the construction of insightful interpretative accounts of experiences (Peat et al., 2019). Preliminary findings of semi structured interviews and social network analysis, using thematic analysis (Braun & Clarke, 2006) will be presented.

The presentation will conclude with a discussion on the implications of the study for policy and practice.

(Im)mobilities of families with wheelchair-using children with cerebral palsy

Emma Landby,

Umeå University, Umeå, Sweden

Mobility is important in shaping people's lives and experiences through places visited and social interactions with other people. In families with children, mobilities are usually complex and include negotiations between various family members, affecting how they move about in time-space. While children in general often are dependent on parental support in relation to transport, children with disabilities tend to be even more reliant on their parents, not least because they are highly car dependent due to social and environmental barriers associated

with other transport modes. This implies that not only disabled children, but also other family members, could be affected by disability related mobility constraints.

My research focuses especially on mobilities of Swedish families with wheelchair-using children with cerebral palsy. Based on interviews, time-use diaries and a survey, I explore how disabling barriers affect families' mobilities in daily life. My findings show that many negotiations and adaptations need to be done to enable mobility for all family members. Oftentimes, it is the disabled child's mobility that is prioritised, which in everyday life often is related to an increased number of trips (e.g. appointments with physiotherapists, doctors and other authorities involved in healthcare) as well as longer distances travelled to reach accessible (pre)schools and leisure activities. Due to inaccessibility with public transport in combination with the children's need for support, parents are often accompanying them, which limits the time available for the parents' own mobilities, impinges on their geographical reach and affect their possibilities on the labour market. A solution to improve opportunities for (independent) mobility for all family members is to have personal assistance in combination with special transport services for the disabled child, which are part of the Swedish support system. However, such support is not always easy to receive.

Parenting in Context: Applying a Critical Disability Studies' Lens to the Qualitative Accounts of Parents subject to Child Protection Investigation for their Children with Disabilities

Susan Flynn,

Trinity College Dublin the University of Dublin, Dublin, Ireland

Despite enduring and significant evidence that children with disabilities are at much higher risk of neglect and abuse than their non-disabled peers (Jones et al., 2012), little research has captured the views and experiences of the parents of these children. This presentation reports on findings of a unique study that specifically captured the accounts of a sample of twelve parents who had been investigated by child protective services within Great Britain and Ireland. The investigation that these parents experienced was with respect to alleged abuse and maltreatment perpetrated by them, against their own children with disabilities. The presentation applies a critical disability studies theoretical lens to the findings. This is to address a gap in disability studies' theoretical scholarship around a matter of utmost importance and urgency to the disability community. Namely, the presence of long-established barriers to effective safeguarding of children with disability (Flynn, 2022). Full ethical approval was granted for the study which involved qualitative semi-structured interviews which were transcribed verbatim and then analysed by the conventions of a framework analysis approach. Findings convey avenues to improve practice with parents of children with disabilities including understanding the emotional and practical implications of experiencing investigation. Findings also reflect the importance of theories of disability studies being utilised to address pressing practical problems for the everyday lives of the disability community, such as the professional safeguarding of children with disabilities.

References

Flynn, S. (2022). 'Critical disability studies and the affirmative non-tragedy model: Presenting a theoretical frame for disability and child protection,' *Disability and Society*, <https://doi.org/10.1080/096875>.

Jones, L., Bellis, M.A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. & Officer, A. (2012). 'Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies.' *The Lancet*, 380 (9845), pp.899-907.

12-05-2023

11:30 - 12:50 - Independent Living in Europe and beyond: past, present, and future Grand Hotel - Gullteigur A /

- Moderator: Teodor Mladenov, University of Dundee

Introduction to the International Journal of Disability and Social Justice (IJDSJ)

Angharad Beckett,

University of Leeds, Leeds, United Kingdom

Prof Angharad Beckett, the Founding Editor and Chair of Editorial Executive of the IJDSJ will introduce the journal and its mission, as they relate to independent living.

Abstract

The International Journal of Disability and Social Justice (IJDSJ: <https://ijdsj.online/editors/aboutus/>) is an international and interdisciplinary journal in the field of Disability Studies. It publishes cutting-edge scholarship and research by authors concerned with challenging injustices relating to disability and building inclusive societies.

Independent Living in Europe and beyond: past, present, and future

Teodor Mladenov,

University of Dundee, Dundee, United Kingdom

This session will introduce a special issue of the *International Journal of Disability and Social Justice* (IJDSJ) on 'Independent Living in Europe and beyond: past, present, and future' and will facilitate a discussion on the topic. The special issue has been edited by Teodor Mladenov from the University of Dundee (UK), and Ines Bulic Cojocariu, Lilia Angelova-Mladenova, Natasa Kokic, and Kamil Goungor from the European Network on Independent Living (ENIL).

The special issue marks the 50th anniversary of the first Centre for Independent Living in 2022, as well as the 20th edition of the Freedom Drive, a biennial advocacy event organised by ENIL. It includes 9 articles and 12 video-recorded interviews with Independent Living activists from 12 European countries. An IJDSJ digest with 'plain English' summaries of the articles and the interviews will be published in mid-December 2022, and the full articles will be published in the IJDSJ in the spring of 2023.

Session plan:

Introduction to the IJDSJ special issue on 'Independent Living in Europe and beyond: past, present, and future' – Prof Angharad Beckett, the Founding Editor and Chair of Editorial Executive of the IJDSJ will introduce the journal and its mission, as they relate to Independent Living; then, Teodor Mladenov and a representative of ENIL will introduce the special issue – in total, 20 min

Presentation by contributors– the authors of one of the research articles (Gabor Petri, Agnes Turnpenny and Aniko Bernat) will present their contribution – 10 min

Screening of a video compilation(subtitled) of the highlights of the interviews with activists – 40 min

Response/commentary by representatives of the Independent Living movement in Iceland– representatives of the Independent Living Centre in Iceland / NPA miðstöðin, in collaboration with Prof Rannveig Traustadóttir – 20 min

Q&A with the audience – 30 min

When legislation is not enough: the adverse environment for independent living in Hungary

Gabor Petri,

Central European University Democracy Institute and TÁRKI Research Institute, Budapest, Hungary

Disability policies in Hungary feature a history of legal progress since the 1990s and EU-funded investments since 2004 but mixed outcomes for disabled people. Thus far it remains unexplored how this paradox plays out in the lived experiences of disabled people and their families. This paper aims to fill this gap by exploring disabled people's experiences of independent living over the last three decades in Hungary.

Based on 53 life course interviews – 34 with disabled people and 19 with family members – we identify seven barriers to independent living that create an adverse environment. We also highlight some facilitators that help people overcome or mitigate the adverse environment. In the conclusion, we discuss trends in Hungarian disability policies that impact opportunities for independent living.

Screening of a video on independent living

Teodor Mladenov,

University of Dundee, Dundee, United Kingdom

Screening of a video compilation (subtitled) of the highlights of the interviews with independent living activists included in the special issue.

Abstract

The video contains highlights from 12 interviews with independent living activists, conducted in the second half of 2022 by ENIL staff members. We interviewed Adolf Ratzka from Sweden, Antonia Trikalioti from Greece, César Giménez from Spain, Diogo Martins from Portugal, Elena Pečarič and Klaudija Poropat from Slovenia, James Cawley from Ireland, John Evans from the UK, Milica Mima Ružičić-Novković from Serbia, Nicolas Joncour from France, Suvad Zahirović from Bosnia and Herzegovina, Vanya Pandieva from Bulgaria, and Vibeke Marøy Melstrøm from Norway. In the interviews, the activists reflect on the impact of Independent Living on their lives. They highlight their advocacy achievements and challenges, and identify their allies and enemies along the way. They also explore current barriers to Independent Living in their countries, making links to the war in Ukraine, the COVID-19 pandemic, Euroscepticism and the cost-of-living crisis. Thinking about the future, the activists discuss Independent Living strategies at local, national, and international levels.

Response/comment by representatives of the Independent Living movement in Iceland

Rannveig Traustadóttir²,

¹ *NPA miðstöðin (Independent Living Center Iceland), Reykjavik, Iceland*

² *University of Iceland, Reykjavik, Iceland*

Representatives of the Independent Living Centre in Iceland (NPA miðstöðin), in collaboration with Prof Rannveig Traustadóttir, will provide a comment on the special issue and independent living in Iceland.

12-05-2023

11:30 - 12:50 - **Education II - Education in national contexts** Grand Hotel - Muninn /

Disability, Inclusion, and Gross National Happiness: The Complex Case of Bhutan

Seyda Subasi Singh¹, Matthew Schuelka²

¹ *University of Vienna, Vienna, Austria*

² *University of Minnesota, Minnesota, United States*

As a part of a significant social transformation in the country, the Bhutanese education system went through a modernisation process in the last sixty years from elite monastic education for few to secular education for all. Education for children with disabilities has also become an educational ideal. However, the gap between the development of policies and implementation of inclusive practice remains profound. The beliefs of Buddhism and the Gross National Happiness (GNH) development philosophy form the basis for the socio-cultural conceptualisation of disability in the country. For example, the concept of *karma* plays a significant role in the Buddhist conceptualisation of 'disability', which elicits mistrust and stigma towards the individual with a disability. There are also many instances in Bhutanese Buddhist belief and practice in which an individual that is not deemed to be 'pure'

or 'whole' is viewed as ineligible from practising *dharma*, or the 'right way of living'. However, there are also complex beliefs and understandings around notions of 'pity' and 'suffering' towards a person with a disability in Bhutan, which motivate a more applied social justice approach towards conceptualising 'disability'— sometimes as an act of charity, but also as a basis to construct a vision of equity and justice via a GNH-based society. The positive attitudes to people with disabilities are mainly attributed to the empathetic behaviour and compassion that Bhutanese people exhibit, and the belief in community-level happiness. In this paper, we describe the conceptualisation of disability through the lens of Buddhism in Bhutan and later discuss the political and public response to the educational goals of inclusiveness. We conclude that there is an opportunity to re-think disability-inclusion through the lens of GNH as a societal value, both in Bhutan and around the world, and present a framework for disability-inclusion in concert with GNH philosophy.

Educational trajectories of young people with intellectual disabilities in Spain: experiences for change and school improvement.

Alicia Vinatea-Elorrieta, Ignacio Haya-Salmón, Susana Rojas-Pernia

University of cantabria, Santander, Spain

This paper is part of a national research project that aims to investigate, from several coordinated teams, school exclusion and inclusive responses in Spain. The research tries to answer the question: What is inclusive education missing? through a multi-agent and multi-argumentative analysis of educational inclusion and exclusion policies. Likewise, and based on the needs detected, the development of participatory projects or actions at different educational stages is proposed.

Specifically, the communication presented here includes the analysis of the barriers and levers identified by 30 young people with intellectual disabilities throughout their educational trajectories and, in particular, in the Compulsory Secondary Education stage. Through biographical-narrative interviews and the use of images (previously selected by the researchers), the participants retrace their school careers, analyse the obstacles encountered and propose possible alternatives to the situations of exclusion experienced within the school context. For many of these young people, the secondary school stage is a turning point in their lives that placing them on different educational itineraries from the ordinary ones and that will substantially condition other life decisions, such as the decision to live independently or to take up employment in an ordinary context.

This first analysis yields an extensive set of educational situations discussed and analysed by the researchers with the support of a team of co-researchers with intellectual disabilities from the University of Cantabria. The project, committed to transfer, aims to be useful to inform about the policies and practices against exclusion in the region in which it is developed.

Implementing and evaluating a national pathway for navigating fieldwork accommodations

Shahbano Zaman¹, Cori Schmitz², Karen Falcicchio³, Jeff Boniface¹, Donna Drynan¹, Laura Bulk¹, Tal Jarus⁴

¹ *University of British Columbia, Vancouver, Canada*

² *University of Alberta, Edmonton, Canada*

³ *McGill University, Montreal, Canada*

⁴ , ,

Introduction: Studies have found a lack of training, expertise, and quality of interventions among those supporting students requiring accommodations. In particular, in health professions education there is a lack of clear, consistent practices for providing accommodations in fieldwork education. As a first step in addressing accessibility in fieldwork, we previously developed a flowchart of recommended procedures for implementing fieldwork accommodations, informed by findings from surveys and interviews of students requiring accommodations in fieldwork, academic fieldwork coordinators, and fieldwork educators. Objectives: To implement the flowchart and assess its procedural efficacy on a national level. Methods: 12 of the 14 Canadian Occupational Therapy programs are currently implementing and assessing their use of the developed procedures. The flowchart includes details regarding “what”, “when” and “who” is involved including checklists for each step of the process. The procedures recommended in the flowchart were implemented by the academic fieldwork coordinators in each of the Occupational Therapy programs. Pre and post surveys and feedback forms were used to collect data from students requiring accommodations, academic fieldwork coordinators and fieldwork educators. To date, we have 12 participants (3 students, 9 academic fieldwork coordinators). Findings: Preliminary feedback from participants suggests that the processes outlined in the flowchart are useful in giving guidance and structure while allowing flexibility for adaptations for program and individual needs. The flowchart and updated results will be shared. Conclusions: Preliminarily, the flowchart is proving a useful resource. These procedural resources are serving as a best practices guideline benefiting both students requiring FW accommodations and faculty who support them. Its transferability to other health education programs can help improve inclusion, participation and diversity in healthcare and service provision.

Securing democratic values or changing society: contrasting approaches to disability rights in Sweden and the United States

Marie Sepulchre,

Lund University, Lund, Sweden

How are similar legal principles interpreted in different contexts? This paper analyses how staff working with accessibility/disability resources in higher education in Sweden and the United States understand disability discrimination. Drawing on vignette interviews, the paper discusses differences in legal consciousness concerning both disability and anti-discrimination rights. In both countries, the participants considered the law as the basis of their work, but differences were noticed regarding their views of the *raison d'être* of laws banning disability discrimination and their potential for changing society. While the Swedish participants tended to consider anti-discrimination rights as obvious principles designed to sustain the values of a democratic state and create a more accessible society, the American participants tended to envision them as an important means to ensure access and tackle ableist structures. While Swedish participants tended to be sceptical about the law's capacity to bring about social justice, most American participants seemed to believe in this capacity but pointed at the need to go beyond strict legal compliance and follow the spirit of the law. The paper proposes that these contrasting views stem from the different histories of anti-discrimination rights in the two countries, which followed a bottom-up process in the United States and a top-down process in Sweden, as well as from the participants' different

understandings of disability. These findings have implications for the study and implementation of disability and anti-discrimination rights in various national contexts.

12-05-2023

11:30 - 12:50 - **Covid-19 II - Health, health care and policy ÖBÍ 1**
Sigtún 42 /

Africa's healthcare system responses to persons with disabilities during the COVID-19 pandemic: what a scoping review tells us.

Lieketseng Ned,

Stellenbosch university, Kuilsriver, South Africa

Background: People with disabilities experience difficulties in accessing equitable health care and this may be worsened during humanitarian emergencies because they are often left behind in these emergency situations. Given these difficulties, it is important to consider how health systems responded to persons with disabilities specifically. We further examine the extent to which disability inclusion is reflected in the said Governments' responses to the COVID-19 pandemic.

Objective: The purpose of our scoping review is to provide an overview of the healthcare system government responses to people with disabilities during the COVID-19 pandemic from March 2020 to March 2022. The specific question is how disability inclusive were the pandemic healthcare system responses?

Methods: The methodological framework used for this review will be guided by Arksey and O'Malley (2005), and supplemented by Levac et al. (2015). The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) and PICOS (Population, Intervention, Comparator, Outcome, and Study) frameworks will be used for reporting. A total of 10 databases (PubMed, Scopus, Web of Science (Social Sciences Citation Index), Africa-Wide Information, PROSPERO, ERIC, MEDLINE, CINAHL, PsycArticles, and Academic Search Premier.) will be searched for English articles published between March 2020 and March 2022 that describe or evaluate healthcare responses to people with disabilities during COVID. Three reviewers will screen abstracts based on the eligibility criteria and extract the data into a predetermined excel form. A descriptive analysis will be conducted to summarize the results and provide an overview of the responses.

Results: The results of the scoping review are expected to be completed by February 2023.

Conclusions: Our scoping review will present the emergency responses taken and synthesise the state of these responses in terms of disability inclusion, as guided by international treaties such as WHO and UN.

'Voiceless' and 'Vulnerable': Challenging How Disabled Children and Young People Were Portrayed and Treated during COVID-19 in the UK.

Anita Franklin¹, Geraldine Brady²

¹ *University of Portsmouth , Portsmouth , United Kingdom*

² *Nottingham Trent University , Nottingham , United Kingdom*

Evidence is emerging of the impact of both the COVID-19 virus and governmental policy decisions during the pandemic which affected the lives of children across the world. Both the immediate, and longer-term impacts of this global unprecedented event are starting to be examined. Disabled children, however, have been afforded little attention in these debates. Yet as a group, disabled children's education, health, well-being and life chances have been disproportionately impacted by; the virus, repeated lock-downs, and 'post-pandemic' responses. Such little focus on this group, and barriers to inclusion and provision in society are not new. Disabled children are often denied their rights to provision, protection and participation.

This paper, co-led and co-written by a UK-based group of Disabled Young Researchers – the RIP:STARS - draws upon our rights-focused research and lived experience. During the pandemic, and more recently through a process of reflective workshops, we shared ideas and collectively decided what we wanted to say. We have been categorised and portrayed as 'the vulnerable' during pandemic responses, without consideration of what that label might mean for the identity of a disabled child and how it might influence disablist attitudes. We argue that disabled children's experiences and voices have not been heard during the pandemic, and subsequently as the world seemingly moves on.

Drawing upon our own pre-pandemic national qualitative research study on holistic rights-focused support for disabled children and young people and our lived experience-, we demonstrate that disabled children and young people should be part of all policy and practice plans for recovery post-pandemic. Far from being 'voiceless' and 'vulnerable' disabled children have much to contribute and can support the development of a more inclusive, rights-based post Covid-19 world. This paper illustrates how co-creation can influence practice and policy in a post-pandemic world.

The possibility of a non-normalizing politics of solidarity

Michael Doblmaier, Alessandro Barberi

University of Vienna, Vienna, Austria

The project *cov_enable: Reimagining vulnerabilities in times of crises* (Austrian Science Fund FWF, P 34641) investigates the impact of the Covid-19 pandemic on students in Austrian schools with a focus on vulnerabilities. The political handling of the pandemic has so far shown two main policy styles. On the one hand (Sweden) tried to find a liberal way of dealing with the pandemic by leaving decisions on how to protect oneself against Covid-19 primarily to the individual. This policy led to a privatization of the risk of infection and endangerment of vulnerable groups. A rather paternalistic policy style prevailed in Austria. Measures were adopted for everyone, which in turn disadvantaged people whose life situation made it difficult to implement all measures as required.

Using the example of the general FFP2-mask requirement, we focus in our paper on the effects of paternalistic policy by presenting the results of a participatory research study with students with disabilities and special educational needs and an analysis of policy documents regarding face mask-regulations in schools.

Our research has shown that such a policy is very susceptible to normalizing effects and thereby excludes certain groups of people. We show that while the policy prescription to wear masks allows for a common approach to the pandemic, and thus potentially a policy of solidarity, it also excludes people. For example, face masks make communication difficult for people who use a wheelchair or communicate in sign language.

Based on this problem situation, we would like to discuss about a policy of solidarity that works without normalizing effects in our presentation. Do we simply have to endure the trade-off between individual vulnerable groups, or is it enough to formulate exceptions and further guidelines for each group? Or is it possible after all to find policies that bring together self-determination and consideration?

Zooming in and out of pandemic safety measures – Inclusive takes on institutional coping and failure in times of polycrises

Oliver Koenig¹, Michelle Proyer²

¹ *Bertha von Suttner Private University St. Pölten, St. Pölten, Austria*

² *University of Vienna, Vienna, Austria*

The COVID pandemic marked a felt threshold into the interconnected effects of the Anthropocene. Its immensity of impacts remaining hard to grasp in a time that cannot fully be perceived as post-pandemic. Such holds true for the pendulum like reversion of achievements made in the struggle for more inclusive systems. The research project “Cov_Enable: Reimagining Vulnerabilities in times of crisis” (FWF Project P 34641) has been tracking related developments. It aims to shed light on how conceptions of vulnerability are being reshaped and travel between the political-, organizational- and the individual level. In particular, we want to disentangle how (new) discourses and practice (formations) in the contexts of (inclusive) education and (supported) living are impacting children, youth and adults labelled as vulnerable and interrelations with ableist/healthist dynamics. This paper will focus on the impact of one of these travelling phenomena. 2022 marked the shift from a singular to Polycrises, in which’s wake the localization of responsibility to uphold protective measures relating to COVID has shifted from the collective to the individual realm while paradoxically political vulnerability discourses having moved from the “individual at risk” to the “vulnerability of systems”. Effects derived will be highlighted by zooming in and out of two vignettes. Vignette # 1 will offer an insight into two specific slots of time, one amidst roaring numbers of infections and accompanying measures, while the other explores sort of a post-pandemic view by stakeholders of different levels of school administration. Vignette # 2 will zoom into the organizational and discursive coping mechanisms of two highly distinct organizations – a sheltered housing provider and a disabled people led cooperative organizing individualized personal assistance schemes. Zooming out provides a magnifying lens in understanding the functioning principles of support paradigms and mirrors the societal shifts and dynamics in addressing issues of dis/ability.

12-05-2023

11:30 - 12:50 - **Health II - Interventions** Hilton Nordica - Meeting Room G /

People with (intellectual) disabilities in physical activity guidelines and recommendations: experiences from three alpine countries

Christoph Kreinbucher-Bekerle¹, Nikolai Kiselev², Wolfgang Ruf³

¹ *University of Graz, 8010 Graz, Austria*

² *PluSport, Umbrella Organization of Swiss Disabled Sports, Volektswil, Switzerland*

³ *German University of Health and Sports, Berlin, Germany*

Physical activity guidelines or recommendations are essential instruments for increasing awareness of the benefits of being physically active regularly. Nevertheless, people with disabilities (PWD) meet guidelines-specific criteria of at least 150 minutes of moderate-intensity physical activity per week at a fraction compared to the general population (Dairo et al., 2016). Until recently, PWD were barely mentioned in such guidelines. Since the renewal of the WHO guidelines in 2020, PWD have been mentioned for the first time (Bull et al., 2020). As a result of the renewal, around 40% of countries worldwide adapted their national guidelines by highlighting PWD as one of the target groups within (Klepac-Pogrmilovic, 2020). However, the depth of recommendations might vary highly between the countries. Whereas in the WHO guidelines, PWD are underlined as a specific target group, the Austrian guidelines highlight PWD in every age and target group (Austrian Health Promotion Fund, 2020). Although PWD are clearly placed in the guidelines emphasizing the same amount and frequency of physical activity as everyone else, there seem to be stereotypes regarding the general population's view on this topic by recommending a lower amount of physical activity to PWD compared to the own physical activity behaviour (Kreinbucher-Bekerle et al., 2022).

Therefore, the aim is to give an overview of the actual physical activity guidelines in the three alpine countries - Austria, Germany and Switzerland - and draw conclusions for other countries. Moreover, two recent studies from these selected regions focusing on people with intellectual disabilities in context of the recommendation for physical activity will be presented. Finally, ideas on how to transfer the content of the guidelines to the target group and to caregivers and how to include PWD in a co-creation process to increase the physical activity levels of PWD will be discussed (Smith et al., 2020).

Having fun as the main outcome of a physical activity intervention for people living with cognitive decline

Tobba Sudmann¹, Frøydís Hausmann², Anne Henriksen², Liljegren Anja², Nistad Valgjerd²,

¹ *Western Norway University of Applied Sciences, Bergen, Norway*

² *Western Norway University of Applied Sciences, Bergen, Norway*

Background: The number of people living with cognitive decline or dementia is increasing as longevity is to be expected. From a public health perspective primary, secondary and tertiary prevention measures are called for. Health is an individual and collective resource, and a social practice. Physical activity (PA) responds to this. Physical activity also affects brain ageing and brain plasticity.

Aims:

Affecting brain function, brain ageing and delayed onset of dementia, sustained or bettered physical function, and increased social participation and civic engagement.

Method:

Participants with subjective or mild cognitive decline, or Alzheimer's disease are included, and are randomized to three arms (music therapy, physical activity, control) after base line tests (cognition, music test, physical performance and fMRI brain scan). Power calculation necessitates 130 participants, aged 50-90. Project period 2018-2023.

The PA-intervention is a weekly 60-minute group-session with basic strength, endurance, balance and coordination and co-operation activities in accordance with HIIT-principles, high intensity interval training. The group are run by physiotherapists, sports scientists, and public health students.

Results:

Recruitment and drop out due to exacerbation of their disease are challenging. The most interesting result so far, is the importance the participants place on the group ambience, and the impact of hospitality and generosity directed from trainers towards participants. This has a direct effect on the adherences to the RCT, weekly turnout, and efforts in PA-activities. Participants and next-of-kin are empathic on this in their feedback. Playing and having fun emerge as a key factor for participation and positive self-reported outcome.

Conclusion:

Social interaction and having fun are key determinants for health and seldom described in interventions for people living with cognitive decline or dementia. This project shows how focus on neuro-regenerations and delayed brain ageing can be intertwined with focus on social participation and wellbeing.

Barriers and facilitators of physical activity for college students with disabilities in Kuwait

Badeer Aldimkhi,

Public authority for applied education and training , Kuwait city, Kuwait

Physical activity is a significant component of public health policy globally due to the adverse health effects of not engaging in the recommended levels of physical activity. There are several health, social and psychological benefits to persons with disabilities partaking in physical activity. Youths with disabilities globally are significantly less active and more obese than their peers without disabilities. The World Health Organization cautions that insufficient physical activity is a risk factor for non-communicable diseases. Kuwait developed a national action plan and strategy for physical activity, which aims among others, to encourage citizens to participate in physical activity and promote physical activity in the school and workplace. Coupled with hot weather conditions, lack of time is a major barrier hindering Kuwaiti college students' participation in physical activity. There is limited research studies on the physical activity in Kuwait focused on college students with disabilities. This presentation will share the findings of an on-going study aimed at determining whether college students with disabilities in Kuwait engage in the recommended levels of physical activity, identify the barriers and facilitators to participation, and generate actionable

strategies to increase their participation in the recommended levels of physical activity. The study employed a cross sectional survey design to collect data from 115 students with disabilities from the Public Authority for Applied Education and Training (PAAET), Kuwait. It used the Global Physical Activity Questionnaire version 2 to measure the physical activity levels of study participants, and the self-administered exercise benefits /barriers scale to assess barriers and facilitators. Preliminary findings revealed fewer students engage in recommended levels of physical activity and the levels are lower among females. Evidence from this study will inform policy and programmatic measures aimed at promoting physical activity among college students and other disadvantaged populations at PAAET and other educational institutions in Kuwait.

Health Literacy and people with disabilities – implementation of UNCRDP in Europe

Katja Valkama¹, Merja Hoffrén-Mikkola¹, Aino Alaverdyan¹, Mika Uitto²,

¹ *Seinäjoki University of Applied Sciences, Seinäjoki, Finland*

² *Seinäjoki University of applied Sciences, Seinäjoki, Finland*

The aim of the presentation is to analyse and describe how people with disabilities are considered in health literacy research in different countries in EU.

The EU Health Literacy Consortium defines health literacy as a personal competence entailing individual's knowledge and skills to search, evaluate, understand, and apply health-related information in everyday decisions related to their own health, how to maintain it, disease prevention and medical care. Digital health literacy, on the other hand, refers to an individual's ability to retrieve this information digitally.

The importance of health literacy, especially digital health literacy for individual's well-being and inclusion has been highlighted due to the COVID-19 pandemic and digitalisation. The presentation explores assessments that have been directed to the health literacy levels of people with disabilities and which measures have been used for the assessments. The data used for this presentation has been collected in a literature review conducted in IDEAHL-project. IDEAHL (Improving Digital Empowerment for Active Healthy Living) -project aims to develop and test new models and approaches of (digital) health literacy interventions and applications through co-creation of a comprehensive and inclusive EU (d)HL strategy. The results are reflected towards the UNCRPD and the presentation focuses on inclusiveness of health literacy policies and practices.

The project "Improving Digital Health Empowerment for Active Healthy Living (IDEAHL)" has received funding from Horizon Europe Framework Programme under GA 101057477. Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or Horizon Europe Framework Programme. Neither the European Union nor the granting authority can be held responsible for them.

Rights-Based Leadership and Governance in Services for People with Disability: What role should evidence have and what should we do if it is ignored?

Malcolm MacLachlan¹, Cathal Morgan²,

¹ *Irish Health Service & Maynooth University, Maynooth, Ireland*

² *World Health Organisation, Copenhagen, Denmark*

The World Health Organisation is currently developing a European Framework for action that seeks to achieve the highest attainable standard of health for persons with disabilities. The Framework envisions that by 2030, persons with disabilities will be fully included and considered in all health planning, delivery and leadership. To support the development of the Framework a Task Group was established on Rights-Based Leadership and Governance, co-lead by the National Clinical Programme for People with Disability in Ireland. The group undertook literature review, and consultations with service user and service provider representative groups. We recommend that persons with disabilities must have accessible information about and access to the services they need ; be central to and involved in the leadership and governance of health services; have their health services provided through the most effective mechanisms of service delivery, particularly in a teamworking context; and that service providers have a right to work in psychologically safe environments, where they feel valued, empowered to question each other and advocate for the rights of service users. As well as presenting these results and the proposed country-level survey tool questions arising from them, we also discuss what role evidence plays in rights-based approaches, and what should be the response of researchers when service providers ignore, or practice in contradiction, of evidence.

12-05-2023

11:30 - 12:50 - **Deafness II with International Sign Language - Education and learning** Grand Hotel - Háteigur /

Promoting print literacy of signing deaf students through an adapted sign language-based educational material

Lina Jerpö¹, Krister Schönström²,

¹ *National Agency for Special Needs Education and Schools , Helsingborg, Sweden*

² *Stockholm University, Stockholm, Sweden*

The literature on deaf education and print literacy in deaf children frequently report challenges for deaf students to develop literacy skills on par with their hearing peers. At the same time, there are deaf students who are successful readers. We argue that the print literacy acquisition in deaf students need a different approach. Often literacy training programs are centred at an auditive-based learning. For example, they are grounded in a *Simple View of Reading* model which emphasizes the importance of using the children's phonological knowledge for the decoding process of reading. The children are then supposed to derive from their spoken language knowledge for the learning to read. For deaf children the starting point is different. When they begin to read, their task is often two-fold. They not only need to learn to decode but also to learn an entirely new language. In Sweden, deaf students are instructed in Swedish Sign language (STS), thus the information is mediated through use of STS in the classrooms. However, there are a lack of effective educational tools in order to promote their literacy development. Our presentation will present development work of an adapted reading program for deaf students. Together, with Stockholm University, the National Agency for Special Needs Education and Schools is

adapting the *Fingerspelling Our Way to Reading* program into STS and Swedish. *Fingerspelling Our Way to Reading* is an evidence-based, supplementary literacy program for D/deaf and hard of hearing students in K-2nd grade in USA. It enhances phonological awareness of fingerspelled words, which increases expressive and receptive fingerspelling skills and identification of printed words. As a pilot project, we will adapt the first level and then test it in our schools. The work with adapting the program started in 2022 and is expected to be ready by the summer of 2023.

Adult deaf emergent readers' learning of print literacy

Ingela Holmström, Krister Schönström

Stockholm University, Stockholm, Sweden

This presentation will highlight and discuss the complex situation when deaf adults who are emergent readers (i.e., with limited or no previous knowledge of print literacy) are expected to learn two new languages in parallel: Swedish Sign Language (STS) and Swedish. Swedish appears primarily in its written form for this group, and therefore, they, apart from learning a new language, also have to develop reading and writing skills. In the hearing context, such learning of print literacy in adulthood is a process that is proven difficult by research (e.g., Bigelow & Vinogradov 2011). In addition, literature on the literacy development of deaf children, frequently reports obstacles with the learning of print literacy for many students even if many become successful readers (e.g., Hoffmeister & Caldwell-Harris 2014). Our study indicates that this is even more complicated for adult deaf emergent readers.

Data comes from ethnographically created video recordings of classroom interaction and interviews with teachers and participants representing this group. The analysis reveals that while the migrants successively learn basic STS skills that allow them to interact with other deaf people in the personal domain and communicate their needs, learning Swedish takes an entirely different path. The migrants struggle with learning basic reading and writing skills, vocabulary, and grammar. Furthermore, although the instruction is highly repetitive, using STS to explain and connect signs with written equivalents, it is unstructured and sprawled without a clear red thread. The teachers testify in interviews that it seems almost impossible for the emergent readers to learn Swedish on a level good enough to cope in Swedish society, which, in turn, puts them in a very vulnerable position. The presentation will conclude with a discussion connecting the results to the Crip Linguistic framework and mark the importance of further research on adult deaf emergent readers.

Mainstream provision models for education d/Deaf pupils in Norway: Connections between institutional structures and teaching practices

Eli Raanes²,

¹ *Norwegian University of Science and Technology, Trondheim, Norway*

² *Norwegian University of Science and Technology, Trondheim, Norway*

In Norway the state deaf schools have been decommissioned. Today, most deaf and hard of hearing pupils attend their local, mainstream school. However, alternative education-provision models have been developed. Five schools have established trans-municipal classes for deaf and hard of hearing children who have NSL as one of their languages. This

presentation is from one such school context. We have led a qualitative research project that examines 1) the teachers' teaching practices, and 2) the organization of the school and the provision of the teaching. As this presentation will mostly focus on the second topic, we will explore: *What institutional structures do teachers mark as important when organizing their teaching?* The data material has been collected from fifteen teachers of twelve classes whose pupils were from six to sixteen years of age. The analysis developed three categories. That is how the teachers are 1) Promoting NSL and bilingual education, 2) Adapting to pupils' diversity, and 3) Collaboration in the D/H teachers' team. Bronfenbrenner's ecological model provides the theoretical point of view for the study, seeing that the macro-, meso-, and micro-levels in society influence each other. According to this theory, the official regulations and the school's organization influence teachers' teaching practices, and thus the pupils' experiences of academic and social inclusion.

12-05-2023

11:30 - 12:50 - **Culture and history II - Lore of disability – at the crossroads of folkloristics/ethnology and disability studies ÖBÍ 2 - Sigtún 42 /**

- Moderator: Eva Þórdís Ebenezersdóttir, Háskóli Íslands

Epictions of functionality and locations of disability in pop-science discourse of 3D bioprinting for therapeutic purposes

Andréa Wiszmeg ,

Malmö University, Malmö, Sweden

3D bioprinting is a highly complex process, in which different printing techniques can be used in combination with (most often) different kinds of pluripotent stem cells. Basically, a printer uses bio-ink to either print tissue by cells in layers, onto a scaffold or in free-form by directions given via software. As of today, advances have been made in the engineering of cartilage, skin (2D), heart valves, bone tissue and also so called organoids; which can best be described as miniature organs with some functionality. 3D bioprinting is a technology, or rather a cluster of biotechnologies, surrounded by lots of futuristic visions with utopian as well as dystopian interpretations. The way it combines different biotechnologies, makes it a possibly very potent tool in on-demand personalized transplantation medicine. The future possibility to create spare parts that will more easily be accepted by the human immune system and require neither human nor animal donors, is an achievement long awaited by medicine as well as by patients in need of an organ transplant. If realized and brought to clinic, it may have the potentiality to reduce or eliminate the need for living or dead organ donation. This paper explores how recent popular science and business discourse on the development of 3D bioprinting technologies depicts and perhaps prescribes certain functionality, when imagining possible future therapeutic applications. It further wishes to problematize how these depictions of functionality in turn expresses disability as located either in the physical person or rather in its environment. Because how is physical disability conceptualized and where is it to be located, when biotechnological developments-such as 3Dbioprinting-make demarcations between person and environment even more blurred? What consequences may such conceptual dissonance have for disability rights discussions?

“He went fishing every day despite being blind”: Understanding blindness and reevaluating the supercrip stereotype in an Icelandic folktale.

Eva Þórdís Ebenezersdóttir,

University of Iceland, Reykjavík, Iceland

Disability understanding is both formed and distributed using language, such as by telling stories. In this presentation an interdisciplinary combination of disability studies and folkloristics is used to explore the 19th century Icelandic folk legend *Álfkonan hjá Vatnsenda* (The hidden woman by Vatnsendi). The analysis is based on a close reading of the legend-text, placing it in the historical context of the time of collection and contrasting that to a modern perception of the legend. The legend is then reflected upon with reference to theoretical notions of embodiment and folk belief. The study reveals how the different social context of the late 19th century and the early 21st century drastically change how the phrase: “He went fishing every day despite being blind”, is understood. Within disability studies and activism, such wording is often deemed as representing the stereotype supercrip which generally is seen as highly problematic and negative. However, Sami Shalk has reevaluated and redefined the term supercrip as a “collection of narrative types” with degrees of meanings rather than a cohesive overarching negative stereotype (2016). Building on Shalk’s redefinition, the paper claims that the folktale *Álfkonan hjá Vatnsenda* is a good example of Shalk’s definition, offers clues to how the understanding of blindness has developed and suggests how the stereotype itself has evolved. The study shows that intersecting disability studies and folkloristics offers fresh insights into tales of lives (real or imagined) lived with difference, the development of stereotypes and disability understanding.

Spatial design and physical impairment in 19th century Iceland

Ólafur Rastrick,

University of Iceland, Reykjavík, Iceland

In recent decades long due interest has been directed at how design and layout of houses has implications for the quality of life for people with physical impairment. Such studies have mostly been directed at modern-day housing, especially in urban areas, addressing questions on access and mobility within homes, workplaces and in public spaces for people that rely on orthopedic support devices or other support equipment. The paper transposes such concerns to past predicaments, exploring the social space of disability in pre-industrial Iceland. On the bases of selected cases of individuals with physical impairment the interplay of disability and the every-day spatiality of the turf-house will be analysed. The impact of the spatial structure of the rural household – as home, workplace and place of schooling and social life – on possibilities of social participation will be explored, in comparison to such possibilities for people with physical impairment in the emerging industrial urban centers of the 20th century. Emphasis will be placed on how the spatiality of the turf-houses generated dynamics between bodies and buildings that differed radically from dynamics in modernist spaces of the industrial cities that were until recently designed in terms of the abled body. The paper entertains the possibility that although inhumane attitudes, primitive support devices and brutal poverty proved to determine the fate of many individuals with impairment in 19th century, the spatial organisation of the turf-house community did to an extent effect

less disability for people with different bodies than the urbanised housing of the 20th century offered.

The brain in a petri dish: A critical disability perspective on neuroscience

Kristofer Hansson,

Malmö University , Malmö, Sweden

Imagine a brain in a petri dish in a biomedical laboratory. Not a whole brain, but a part grown with the help of cells. Through this collection of cells, the researchers perform various experiments. It may involve testing different disease models or experimenting with specific drugs to see how the brain cells react. The researchers can also remove, add or turn off specific genes to see how this brain reacts. Through these tests, medical knowledge is produced about the brain, but also about different brain diseases and treatments. Some of this neuroscientific knowledge can give medical understanding for developmental disability. It is knowledge that can be used to create diagnoses and classification systems which strengthen what we as critical disability researchers would call the medical model. These diagnoses and classification systems are not defined entities, but heterogeneous parts in the medical model. They are, one could say, in various ways linked back to the brain cells in the petri dish. The different parts are an assemblage where the medical knowledge about a specific developmental disability are linked to the materiality in the laboratory, as well to the doctor at the hospital or the person seeing the doctor. In this way, we as disability researchers might be able to transform our cultural framework, we use to criticize the medical model and turn this critique to the laboratory. Is the medical researcher's work with the brain cells in a petri dish a practice that (re)produces not only the assemblage of what developmental disability is, but also the stigmatized and negative identity that many times exists in society around this disability? In this paper I want to elaborate critical disability theory to see if it can be used to understand the knowledge production practices in and outside the biomedical laboratory.

The power of museum objects: problematizing disabling discourses around the Portuguese case

Patrícia Roque Martins,

Art History Institute / FCSH/ Universidade NOVA de Lisboa, 1099-085 Lisboa, Portugal

Each museum object has an epistemological potential and a particular narrative that is often unexplored and largely unrevealed in museum representations and discourses. In fact, in most cases, museum objects end up being used peripherally, as accessories of a narration of another story and not as the focus of a story in itself.

This paper aims to question museum stories about disability, traditionally associated with culturally derogatory meanings and stereotyping practices, focusing on the Portuguese case. It will explore and discuss the objects representing disability, either through the way they were visually presented since their origin - from antiquity to contemporary times - or through textual narratives that were developed by museum professionals to contextualize and/or describe them, as part of the museums public collections.

In this regard, this paper it will focus on the power of intangible interpretive practices built around the material culture of disability, questioning the way in which they become "accepted facts" about a certain reality, assuming a fundamental function throughout the history of the social and the human western culture. This paper will also focus on the power of museums agency to transform culturally rooted meanings about disability, pointing to new possibilities in disability discursive interpretations and representations. In fact, the potential that museums have to problematize disability thematically, exploring questions concerning human diversity, non-normative bodies and ableism concept, deepening invisible stories about disability socio-cultural heritage, will be our main key argument. The idea is to discuss how museums studies could intersect with the disability studies arena, namely, in the production of disability collective identity and culture, building up new insights for the creation of more fairer narratives about disabled people contributing for its inclusion and for the creation of new social roles.

12-05-2023

11:30 - 12:50 - **Inclusion IV - Parenting 1** Grand Hotel - Útgarður /

Overcoming the residue of eugenic beliefs: social challenges experienced by disabled parents

Claire Azzopardi Lane , Matthew Vassallo

University of Malta, Msida, Malta

Raising children in today's society might be seen as an undervalued occupation, but for disabled parents the challenge is to overcome the culture's refusal to recognize them as competent parents and functional family units. As part of a wider project, this paper involved exploring experiences of disabled mothers in a Maltese socio-cultural context. The rights of disabled parents are endorsed in Malta's National Disability Policy, its Strategy and the Positive Parenting National Strategic Policy. Seven disabled parents from various impairment groups and two social workers working with disabled parents were interviewed. Thematic analysis was used to analyze the data. The findings showed a residue of eugenic beliefs still present in society, especially when parents lived with an intellectual disability. Lack of accessibility, support and resources, ableism, disableism, invisibility and assumed incompetence were also prevalent. A number of recommendations were extracted from the data and presented to the national disability services agency for implementation.

Perplexing Presentations: Compulsory Neuronormativity and Cognitive Marginalisation in Social Work Practice with Autistic Mothers of Autistic Children

Katy Benson,

Cardiff University, Cardiff, United Kingdom

In recent years, there has been growing interest in exploring the experiences of autistic adults through a lens that adopts emancipatory theorizations of autism. However, despite this changing terrain, autistic people remain a highly subjugated population. Research has

begun to theorise a distinctive form of epistemic injustice they encounter in which they are denied access to epistemic resources by a society that valorises cognitively normative ways of being, knowing and existing.

An under-explored aspect of this emerging literature relates to the experiences of autistic mothers who are, themselves, much more likely to have autistic children. Evidence suggests they may be at a substantially increased risk of involuntary social work interventions.

This study explores the nature of these experience, drawing on interviews with autistic mothers as well as my own, lived experiences as an autistic mother in the UK. It finds that, through a neuro-normative lens of social work scrutiny, indicators of neuro-divergency in both mothers and children are considered *perplexing* and assigned malign meanings by those with hermeneutic privilege. This was particularly evident in social work responses to children's difficulties in attending school, with these difficulties located in mothers rather than in exclusionary, hostile school environments. It finds that neuro-normative, ableist notions of "good motherhood" – and a hegemonic, neoliberal privileging of normalcy and self-sufficiency - create an exclusionary standard which autistic women consistently fall short of. It concludes that social work interactions with autistic mothers in the UK are imbued with ableist discourses which in turn, work as part of a broader machinery serving neoliberal interests.

Reflections Of Adult Children of Parents with Intellectual Disabilities

Tammy Bachrach,

Azusa Pacific University, AZUSA, United States

This multiple case study explores the phenomena of being raised by parents with intellectual disabilities from the adult child's perspective. Autoethnographic data was collected from the author and 4 non-disabled adults who were raised by mothers who had intellectual disabilities. The significance of the parent's disability, parent/child relationship and the social factors that either hindered or facilitated the family are discussed. This study found that the majority of the families were at risk of losing custody of their children and that extended family or support services protected the family unit and provided valuable support to the children. It was common for the participants to have additional responsibilities growing up. All of the adult children achieved typical adult outcomes. The adult children interviewed typically did not define their maternal relationships in terms of disability or limitations and all maintained a strong relationship with their mothers.

A Robot doesn't judge, does it? - How Robotics can reproduce Ableism

Alice Schippers¹, Jane Strugar Kolečnik²

¹ *Disability Studies in Nederland/Universiteit Voor Humanistiek, Utrecht, Netherlands*

² *Disability Studies in Nederland, De Meern, Netherlands*

In this presentation, we examine the concept of robotic assistants as a "distributed" prosthetic in the lives of parents with intellectual disabilities, especially in the context of family life. A robotic prosthetic could make the disabled person feel "highlighted" if it is not integrated into the disabled person's body as the aforementioned "distributed" object."

Through this process, parents who require robotic prosthetics may feel as if the social value of their role as a parent is reduced because of their need to rely on a robot in their daily lives.

To more closely examine the social role of parenthood and the impact of a robotics on agency within parenthood, the authors draw on experiences of mothers both in the Global North, and in the Global South. From our current original research on assistive technologies for disabled parents we examine first the integration of robotics into the daily practices of disabled parents. The role of robots as "distributed" objects will be examined, particularly in the scope of the family. Therein, how different members of the family interact with the robot - including a parent with intellectual disabilities - affects the extent to which the robotic prosthetic is "distributed" and how it relates to the disability of the parent. Finally, the authors examine the question of whether this process of distribution would come more easily to parents with intellectual disabilities because the robot is a non-human actor which, superficially at least, "does not judge." We conclude by examining the idea that the feelings of being judged may be external, perceived by the persons with intellectual disability as being stigmatised for needing a robotic assistant to begin with, and its relation to the perceived neutrality of technology.

12-05-2023

13:40 - 15:00 - **Inclusion IV - Parenting 2** Grand Hotel - Útgarður /

“I didn’t know you could get a social worker just for you”: The role of adult social workers in supporting parents with intellectual disabilities.

Beth Tarleton¹, Gillian MacIntyre ², Kate Precious¹,

¹ *University of Bristol, Bristol, United Kingdom*

² *University of Strathclyde , Glasgow , United Kingdom*

Parents with intellectual disabilities (ID) often require support to ensure their children’s wellbeing. A growing body of international literature has highlighted the barriers that parents face in accessing support as well as identifying good practice. In England, parents with ID are entitled to support for parenting under the Care Act, yet we know very little about the role of adult social workers in providing support for this group of parents. The aim of this study is to investigate how social workers from generic adult and specialist learning disability teams identify, engage with and support this group of parents across five case study sites in England via an analysis of relevant policy documents, interviews with key informants, focus groups with social workers using a vignette to explore professional decision-making and interviews with parents with ID on their lived experience of receiving support. Our work is informed by social practice theory which suggests that practice can be analysed to understand how forms of behaviour emerge and take root in professional practice via meanings (assumptions, attitudes, understandings), materials (resources available) and competencies (knowledge and skills of practitioners). This framework allows us to consider the ways in which ableism and stigma might create barriers to support for parents with ID. We will present preliminary findings from one or two case study sites identifying the key factors that inform professional decision-making around supporting this group of parents. We will provide an analysis of the priority given to supporting parents with ID, including social workers’ attitudes to and understanding of parents needs and their legal right to parent We

will also consider the lived experiences of parents with ID who have received support to parent from an adult or LD social worker.

“I was worried about not being good enough”. Experiences and perspectives on pregnancy, childbirth and parenthood when living with a neuromuscular disorder

Ann-Lisbeth Højberg, Charlotte Handberg, Pia Myrup

The National Rehabilitation Center for Neuromuscular Diseases, 8000 Aarhus C, Denmark

Parents with neuromuscular disorders (NMD) experience challenges related to pregnancy and parenthood. However, research in this field is sparse. The aim was to explore everyday life experiences and perspectives on challenges of parents living with neuromuscular disorders (NMD) and identify important elements to take into consideration for the couples and their health professionals. 27 people (17 with NMD and 10 without), were included. The participants were parents to children up to three years of age. Three types of semi-structured interviews were applied: four dyad interviews with couples where one part had NMD, two focus group interviews with people with NMD, and seven individual interviews with partners to people with NMD. The data analysis was guided by the Interpretive Description methodology and the Antonovsky's Sense of Coherence Theory (SCO). The findings illuminated five categorical themes. (1) *Enforced Dilemmas*: how the couples when choosing to become parents went through dilemmas on the possibility of passing on the NMD. (2) *Reflections on Bodily Ability*: the effect that pregnancy and parenthood had on the body. (3) *Concept of Normality*: the concerns the parents had about 'not being good enough' or 'normal enough'. (4) *Experience of Dependency*: being dependent on especially the other parent, relatives, or the children. (5) *No One to Emulate*: the rarity of the MND made it difficult to find other families to mirror or to get advice from professionals. The findings illuminate important elements to take into consideration for couples with one part with NMD or when being a health professional supporting and providing knowledge for the families.

Fatherhood - adults with profound intellectual disabilities. A qualitative study from Poland

Diana Aksamit, Barbara Marcinkowska,

The Maria Grzegorzewska University, Warsaw, Poland

Introduction: Little is known about the experiences of fathers who care for adult children with profound intellectual disabilities. The aim of this study was to explore these experiences from their perspective. For the purposes of considerations about profound intellectual disability of adult sons and daughters of the male respondents, we have adopted the following definition of disability: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which may, in interaction with various barriers, hinder their full and effective participation in society on an equal basis with others" (Article 1 of the Convention on the Rights of Persons with Disabilities, drawn up in New York on 13 December 2006, Journal of Laws of 2012, item 1169).

Methods: Researchers conducted narrative interviews with 32 Polish fathers with adult children with profound intellectual disabilities. The information was shared during the participant interviews using analytical methods, based on theoretical and methodological concepts developed within the biographical sociology framework outlined by Fritz Schütze (1977, 2012). The respondents were asked to share their thoughts about their experiences as fathers from past, present and future perspectives.

Results and implications: The qualitative research methodology and the applied biographical approach made it possible to take into account many important aspects of fatherhood and thus the course of biography: masculinity in a social perspective: requirements, norms and in a subjective perspective: what meanings and senses do men give to their own masculinity individually, its significance for fulfilling the role of a father, the formation of fatherhood over the years; the events in the biographies of fathers of adults with profound intellectual disabilities can be called critical, marked by the trajectory of experiences, the significance given to it by the interviewees, and how they perceive the future of their adult children with profound intellectual disabilities. Gaining a better understanding of and uncovering details about the fatherhood experiences of men with adult children with profound disabilities is important so as to better understand ways to better support fathers in such situations. It is especially important to know about the ways in which these fathers perceive their experiences and to understand the social context that impacts their experiences and perceptions.

Parental mentalizing among mothers with mild intellectual disabilities: The role of socioeconomic risk and childhood experiences of abuse and neglect

Mårten Hammarlund, Tommie Forslund, Mia Breitholtz, Pehr Granqvist

Stockholm University, Stockholm, Sweden

Background: Parental mentalizing – the capacity to understand children’s behavior in terms of intentional mental states – plays a key role in parenting (e.g., Luyten et al., 2017). Parents with intellectual disability run an elevated risk for caregiving problems, and it is a common preconception among professionals that parental mentalizing difficulties are inevitable among the mothers in question. Empirical knowledge on parental mentalizing in this population is, however, completely absent. We therefore investigated parental mentalizing among mothers with mild intellectual disability, and a clinical comparison group comprising mothers with ADHD. Additionally, since parental mentalizing has been found to be negatively affected by experiences of maltreatment and psychosocial risk – experiences that are overrepresented among mothers with intellectual disability (Hammarlund et al., 2022) – we also examined the role of such experiences for the mothers’ mentalizing capacity.

Method: Data was collected following ethical approval and feedback from two mothers with intellectual disability. 30 mothers with mild intellectual disability, and 61 mothers with ADHD, completed a comprehensive background interview, adapted to the mothers’ cognitive needs. The interview included questions about psychosocial risk factors, and about childhood experiences of abuse/neglect. Answers were used to create cumulative indexes. The mothers were contacted a year later for assessment of parental mentalizing, responding to the parental reflective functioning questionnaire (PRFQ; Luyten et al., 2017) in an interview format with cognitive support.

Results: Mothers with intellectual disabilities reported significantly more non-mentalizing modes of understanding their children’s behavior. At the same time, a notable proportion of

these mothers did not display mentalizing difficulties. Multiple regression analysis also showed that more pronounced mentalizing difficulties among the mothers were related to more severe exposure to abuse/neglect and psychosocial adversity.

Discussion: Our findings indicate that mothers with intellectual disability, as a group, are at risk for mentalizing difficulties. However, the notable heterogeneity among the mothers, and the demonstrated role of abuse/neglect and psychosocial risk, caution against simplistic conclusions whereby mentalizing difficulties are assumed and attributed to intellectual disability per se. Rather, our findings support contextual models of caregiving among mothers with intellectual disability (e.g., Feldman & Aunos, 2020), and highlight the importance of preventive work targeted against psychosocial inequality. Our findings also suggest that mentalization-based support may be fruitful for supporting parents with mild intellectual disability.

12-05-2023

13:40 - 15:00 - **Services II / Employment - Accessibility and universal design** Grand Hotel - Huginn /

Disability Narratives in Québec City, Canada: Ethnographic Study of Urban Mobility and Social Participation

Juan Mansilla, Normand Boucher, François Routhier

Université Laval (Canada); Cirris Research Team; CIUSSS-CN, Quebec City, Canada

This presentation analyzes how people with motor disabilities in Quebec City (*i.e.*, study participants) build their experiences of mobility and social participation based on environmental, technological, and social conditions [\[1\]\[2\]](#) found in their life trajectories. To answer this question, we have compared the life trajectories of 12 participants —four women and eight men with an average age of 48 years old— and their multiple social relationships.

Following the experiential narratives of the participants, we have developed a multi-situated ethnography strategy of social actors that influence the way participants use public spaces and perceive disabilities: community associations, health services, public transport organization, government. This strategy, combined with a participatory research approach (interviews, community mapping of daily activity areas, video-elicitation) allowed us to develop a narrative analysis[\[3\]](#) of the object research.

Our results show that, for the participants, self-determination —actions and beliefs necessary to engage in “autonomous” mobility[\[4\]](#)— is an ideal threatened mainly by physical factors (the state of the sidewalks, lack of clearing snow in winter) and political decisions (deterioration of the adapted public transport, bureaucracy of social assistance). Even if the participants point out the physical and political obstacles to their mobility, the social stigma of disability remains the fuel of their life trajectories and social participation. All of them share a common trait: their mobility in the city is built on their civic engagement[\[5\]](#), not only for the

promotion of human rights of people with disabilities, but also in different social spheres, beyond the disability *milieu* (women rights, inclusion of migrants, cost of living).

From a mobility and inclusive social participation perspective^[6], this study emphasizes the need to accompany current inclusive urban planning and public policies in Québec City, with wide-ranging community actions to raise awareness of disabilities narratives and civic engagement of people experience physical and mobility impairments.

Through Transportation to Participation: Experiences in Using Paratransit Services

Selina Egger¹, Armin Gemperli², Martina Filippo³, Ronald Liechti⁴, Brigitte Gantschnig¹

¹ ZHAW School of Health Sciences, Winterthur, Switzerland

² University of Lucerne, Lucerne, Switzerland

³ ZHAW School of Management and Law, Winterthur, Switzerland

⁴ Foundation Behindertentransport Kanton Bern, Bern, Switzerland

Background: Paratransit services are an important option for persons who cannot use public transportation or can do so only to a limited extent (e.g., persons with disabilities). The use of paratransit services is limited due to financial and structural reasons. These limitations lead to disadvantages for persons with disabilities in using transportation compared to the rest of the population.

Objective: This study aimed to investigate the experiences and needs of persons with disabilities using paratransit services in Switzerland. We examined facilitators and barriers to the use of paratransit services and the influence of these factors on participation in different areas of life.

Methods: We adopted a qualitative approach with five focus group discussions, including 31 participants overall. We collected data between July and October 2021 and analyzed the data using content analysis.

Results: Paratransit services are experienced as an important and appreciated alternative to public transportation. Facilitating factors (e.g., habits, health condition, activities, safety, accessibility, service) and barriers (e.g., high costs, good or bad weather) influence the individual use of and need for paratransit services.

Conclusions: In the area of transportation, persons with disabilities are at a disadvantage compared to the rest of the population. This leads to participation restrictions in different life areas, especially in the areas of leisure or acquisition of necessities.

Between principle and practice – local endeavors of implementing Universal Design in Sweden

Emil Erdtman, Per-Olof Hedvall, Kirsten Rassmus-Gröhn

Lund university, Lund, Sweden

Universal design (UD) has in recent years been included in Swedish governmental policies for procurement, standardization, architecture, design, etc. UD addresses persons with disabilities as part of human diversity. It is defined in the CRPD article 2 and clarified in the CRPD Committee's General Comments 2 and 7.

This study yields an in-depth picture of the conceptions and practices of UD in Sweden. It is based on a qualitative content analysis of a diverse dataset consisting of individual interviews (including go-along interviews), group sessions, workshops, and participant observations in three Swedish cities. A diversity of perspectives was sought, using – as one of the tools – the Quadruple Helix (QH) model, which distinguishes knowledge areas of public, business, academic, and civil society sectors. 55 persons participated in the (group) interviews and workshops, and approximately 100 were involved in the observations.

The findings show a variety of ways of talking about UD – as a guiding, striving, and unifying principle. UD was related to flexibility, non-categorization, and sustainability. It inspired new working methods and was used strategically. However, discrepancies were also identified, e.g., between short-term demands and long-term learning.

Further, the observation of the urban design processes, in which local disability organizations were involved, suggests challenges related to the practice and implementation of UD. It appears that different approaches to collaboration and processes caused uncertainty and mistrust; organizational inertia and an uncritical implementation caused tensions; and requirements of UD faded along the way while committed civil servants challenged the conventional practice in collaboration with disability organizations.

Based on these findings, the paper argues that UD must be contextualized in every local situation because the vision of an inclusive society may be counterproductive if it is too distanced from real experiences. Compliance with the CRPD must be combined with openness to innovative processes.

Exploring a Universal designed space for research in Creative Workshops

Hilde Guddingsmo,

Nord University, NAMSOS, Norway

The presentation aim to focus on which basic attitudes should form the premises for the work of creating an inclusive research setting, in the span between training and universal design.

The empirical data come from the exploration of creative workshops as an approach for developing improved methods for research participation for persons with learning disabilities. In the workshops, we used drama-based work-tools with improvised role-playing games. In the facilitation, continuous adjustments were made between the group's focus and choice of conventions. Further, the work- methods emerged through the group-members application of the tools.

This implies an adaptation based on a social model of disability, with the intention of creating a universally designed research setting. We experienced that we managed to create an inclusive space for participation, which however could not meet the criteria of being referred to as inclusive research. At the same time, it can be argued that the way of working offers enhanced opportunities for influence, based on recognition of the individual's distinctive contribution.

Thereby, our experiences becomes part of an ongoing debate within the field of inclusive research, where the ideal of influence at all stages of the research process can contribute in making demands on the competence of the co-researchers. This has helped to promote educational programs that provide training to become co-researchers on a par with

researchers. The presentation intends to discuss whether this also can contribute to raise the competence requirement for co-researchers to an extent where research no longer will be inclusive.

It will further seek to lift the discussion to deal with which premises are most important when doing research inclusively; the correct kind of research or the group's unique and self-perceived perspectives.

12-05-2023

13:40 - 15:00 - **Policy and theoretical perspectives IV - Revisiting a Nordic Approach to Disability** Grand Hotel - Gullteigur A /

- Moderator: Hisayo Katsui, University of Helsinki

“You mustn’t call it a hobby!”: Challenges in providing meaningful lives to persons with profound intellectual disabilities within the Finnish system

Eero Saukkonen,

University of Helsinki, Helsinki, Finland

Over the past decades, both before and after ratifying the CRPD in 2016, Finland has undertaken various efforts to improve the lives of persons with intellectual disabilities. Such efforts have concentrated on various elements, such as housing, employment and participation in the field of leisure activities. While many challenges remain, persons with severe or profound intellectual disabilities continue to be at a particular disadvantage, and in some cases measures intended to improve the lives of persons with disabilities in general have ended up further marginalising persons with greater assistance needs and more severe limitations in communication.

In this presentation, I look at some of the particular challenges that persons with severe or profound intellectual disabilities and their families face within the current support structures in Finland. Whether through the limitations imposed by a continuous need for assistance, unfavourable interpretations of existing policies by public officials, or market forces in the field of professional personal assistance, these persons encounter obstacles to living meaningful and unique lives that are sometimes amplified by the severity of their impairments, and sometimes entirely exclusive to their particular diagnoses. Focusing on persons with severe or profound intellectual disabilities highlights not just the existing barriers to full participation that persons with disabilities face, but the current inequalities between persons with different kinds of disabilities, as well as the problems of applying identical policy criteria to persons with unique needs.

This presentation is informed by ethnographic and video diary data produced between 2020 and 2022 as part of my ongoing thesis study, which has focused on the lives of half a dozen young people with severe or profound intellectual disabilities living across Southern and Central Finland.

Construction of a model – deconstruction of the user. A critical perspective on the Swedish working method IBIC (the individual's needs in focus).

Gunnel Andersson, Kristina Engwall

Uppsala University, Uppsala, Sweden

This study scrutinizes if and how the working method/model/support IBIC (The Individual's needs in focus) facilitates a social perspective on support to individuals with psychiatric disabilities. IBIC is utilized in the Swedish social service's assessment process and the implementation of interventions to individuals with disabilities. It is recommended by The National Board of Health and Welfare and nine out of ten Swedish municipalities have implemented or are going to implement IBIC.

However, there are neither evaluations nor research concerning the premises of IBIC or the outcome. It is not even evident what IBIC actually is. IBIC is described as a 'support', a 'working method' and as a 'model' in the guidebook. IBIC stipulates that the social service's interventions should be based on the individual's needs rather than of the range of interventions usually offered by the municipalities. There should also be an increased focus on the individual and participation. IBIC is also supposed to assist individual and organisational follow-ups and to offer preconditions of an evidence-based practice. IBIC has great similarities with structured documentation with preset headings and scales.

IBIC is based on WHO's international classification of functional status, disabilities and health (ICF), which primarily is used by the health sector. It is debatable if a language aiming at describing 'health' is relevant for describing social support. Likewise, it is important to ask if the tightly structured documentation systems of IBIC actually promotes the 'client's voice' and participation. Research has discussed a gap between the intended qualities of structured documentation and their compatibility with social work.

This study critically explores IBIC through community-based social support for individuals with psychiatric disabilities. The study is qualitative based on analyses of social documentation and interviews with social workers from five municipalities. A social perspective on psychiatric disabilities guides the study.

International Investigation of Orientations towards a Positive School Climate for Diversity

Svenja Hammer¹, Kara Mitchell Viesca¹, Jenni Alisaari², Svenja Lemmrich³

¹ *NTNU, Trondheim, Norway*

² *University of Turku, Turku, Finland*

³ *Leuphana University of Lüneburg, Lüneburg, Germany*

Article 24a of the CRPD states that "States Parties shall ensure an inclusive education system at all levels and life long learning directed to [...] [t]he full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity".

Against this backdrop, the presented study took school as a main organization for education into focus and developed a framework of orientations for a positive school climate that are based on research that shows that it can improve students' wellbeing and life-satisfaction, reduce minoritized youngsters' experiences of discrimination and thus predict better belonging among them.

The five orientations are Agency (Teaching/Learning Grounded in Self-Determination), Reciprocity (Teaching/Learning that Produces Belonging), Openness (Teaching/Learning that Embraces Multiple Knowledges and Perspectives), Curiosity (Teaching/Learning for Growth Through Exploration and Inquiry), and Creativity (Teaching/Learning that Generates Possibility and Transformation).

In this multi-site, qualitative study we are asking teachers and students what their perceptions of the orientations are and how they can be put into practice. Furthermore, we are asking what their definition of *diversity* is, and if disability is represented as human diversity. We conducted focus group interviews.

This is an ongoing study, so this presentation is based on a preliminary analysis of data collection from Finland, Norway, Germany, England, and the US.

Across all contexts, teachers agreed that the five proposed orientations are important for a positive diversity climate. Especially in Finland, Norway, and Germany participants stated that the resources are missing to implement all aspects equally, namely personnel and time. It was repeatedly highlighted that a feeling of belonging is particularly important to create a positive diversity climate.

Learning about the resources that teachers see necessary, can provide knowledge about a positive school climate, and address diversity also to include pupils with disability.

Revisiting a Nordic Approach to Disability

Hisayo Katsui¹, Marianne Hedlund², Kristina Engwall³

¹ *University of Helsinki, Helsinki, Finland*

² *NTNU, Trondheim, Norway*

³ *Uppsala University, ,*

This session starts with this presentation to pave the way for the following three papers from three nordic countries. We first review the trajectory of the development of the Nordic approach to disability and then analyse the current contextual realities that are increasingly dynamic and different from the time when the approach was established.

Nordic countries have long enjoyed the reputation of welfare states that have extensive disability services for persons with disabilities. In The Nordic approach to disability has been attracting increasing attention not only due to the fame of the welfare states but also due to its long-standing academic tradition of using a relational approach to disability. Professor Jan Tøssebro and Professor Rannveig Traustadóttir have contributed with valuable publications and papers at the NNDR conferences about this. . In this session, we will revisit this approach and explore needs for change or new insights in this approach. This is due to the changing contexts of our welfare states including the influence of new public management, austerity measures, and lack of understanding of disability as a human diversity, not a special or needy group. We also discern tendencies where support becomes more and more related to medical diagnoses despite public disability policy embracing equity and citizenship for persons with disability. We will also discuss how attempts of standardization of welfare services within the area of disabilities are used as an argument to enhance legitimacy and create preconditions for evidence at the same time as it might decrease professional discretion. There is also a need for a discussion how, and if, the service users' voices are possible to include in highly standardized methods.

We will demystify the Nordic approach to disability, rethink and challenge the need for change in academic tradition and foundation of the Nordic approach to disability.

12-05-2023

13:40 - 15:00 - **Work and employment II - Accommodations** Hilton Nordica meeting room I /

IPS and SEd for young adults with mental health problems in a Swedish welfare context. Managers perspectives on the support and views on responsibility.

Maria Hillörn¹, David Rosenberg¹, Helene Hillborg², Veronica Lövgren¹

¹ *Umeå University, Umeå, Sweden*

² *Region Västernorrland, Sundsvall, Sweden*

Young adults with mental health problems often experience obstacles in completing education or getting and keeping work. As these are natural pathways in transitioning into adulthood and gaining independence there is a need to provide effective support. Two methods are Individual Placement and Support (IPS) and Supported Education (SEd) with a focus on individual capabilities and goals. Apart from helping people become self-sufficient, through success in work and studies, they have shown positive outcomes such as higher quality of life and mental health recovery. Despite strong evidence and IPS being a recommended intervention in Sweden, few organizations have implemented the method. Mental health problems are costly for society in terms of need for support but also in individual suffering and marginalization. It is therefore important to explore the reasoning for offering this support in a Swedish welfare context and how these interventions can help young adults with mental health problems to a sustainable work life and better mental health.

The study's aim is to explore and describe the perspectives and reasoning of managers in social- and healthcare organizations, when reflecting on responsibility and strategies in offering support to young adults with mental health problems who wish to study or work.

Qualitative semi-structured interviews are currently conducted with middle management in organizations providing support through IPS and SEd. The interviews focus on the perspectives from their role as managers and are analyzed using qualitative content analysis.

Preliminary results show that even sites working with IPS for a long time with good results, many rely on external financing for implementing educational support. IPS and SEd builds on co-operation with other welfare actors and this often poses a difficulty, but support and co-operation within their own organization seems to be the most important factor to sustainably offer effective vocational and educational support.

What goes into a disclosure decision? Understanding the communication goals and workplace factors considered by workers with episodic conditions when needing support.

Monique Gignac¹, Ron Saunders¹, Arif Jetha¹, Lahmea Navaratnerajah¹, Julie Bowring¹, Peter Smith¹, Aaron Thompson², Renee-Louise Franche³, Curtis Breslin¹, Carolyn Minnick¹

¹ *Institute for Work & Health, Toronto, Canada*

² *University of Toronto, Toronto, Canada*

³ *WorkSafeBC, Vancouver, Canada*

Objectives: Decisions to disclose a disability to others at work are particularly complex for people with conditions that result in episodic work disability (conditions that are often invisible and can fluctuate over time). This study aimed to understand the disclosure goals of individuals working with an episodic physical and/or mental/cognitive disability, whether sharing information was perceived as helping to meet goals, and the role of perceived need, personal communication preferences, and workplace policies in disclosure decisions.

Methods: An online, cross-sectional survey was administered in Canada to 737 respondents (48% women; 50% men; 2% non-binary) living with physical and/or mental/cognitive conditions that created employment limitations at least some of the time. Measures included personal characteristics (e.g., age, gender, education), work context, disclosure goals, disclosure need, communication preferences, support, and communication outcomes. Descriptive and multivariable regression analyses examined the data.

Results: Fifty-eight percent of participants had disclosed support needs to their supervisor although fewer than half (43.4%) the sample reported specific work-related goals they considered in deciding whether to disclose. When provided with a list of specific goals (e.g., receiving support, building relationships with others, future career opportunities, maintaining one's reputation) there was considerable variability in perceptions of whether disclosure of a goal would help achieve it. Participants with both physical and mental/cognitive conditions were more likely to have disclosed while those with mental/cognitive conditions were less likely to have disclosed ($p < .001$). Current health and job needs, personal preferences, and workplace perceptions also were significantly related to disclosure.

Conclusions: Findings highlight the need for workplaces to go beyond condition type to improve workplace support. This includes potentially modifying communication and support policies and practices to help workers manage privacy preferences and uncertainty in defining and meeting support goals.

Disability and Work. Sociological insights on issues related to the disclosure of disabilities

Normand Boucher, Veronique Garcia

Université Laval, Québec, Canada

People with disabilities represent one of the most disadvantaged groups in the labour market in most contemporary societies, as illustrated by key indicators such as the employment rate. These differences persist despite the various laws, policies implemented in Canada, to support people with disabilities' preparation, integration, and retention in our contemporary societies.

Objective: This conference aims to discuss issues related to the disclosure of disability - or non-disclosure - by people who are seeking jobs or are at work as well as the factors influencing this phenomenon.

Methodology: A large study (Disability, Employment, and Public Policies Initiative) allowed the research team to conduct over 200 qualitative semi-structured interviews with people with physical disabilities who were seeking a job or were at work in Québec and New Brunswick. These outcomes draw on thematic analysis from a subgroup of 29 people who had been at work since at least 5 years and selected randomly among all participants.

Results: Findings show that few participants refused to refer to their disabilities before being hired, at the time of hiring or at work. Even if they perceived the labour market as a source of discrimination for themselves, most of them considered that there are more benefits than risks related to the disclosure. Factors such as type of workplace, labour market perceptions, acquired skills and support from employment organisms, as well as visibility of disabilities all have an influence on the personal experience and choice to disclose. These findings will be discussed in light of identity social practices and ableism structuring effects of individual /society relationship.

Conclusion: By this analysis, we are also hoping to contribute to a sociological understanding of the persisting gap regarding integration and retention at work among persons with disabilities and without disabilities.

Developing a work accommodation operating model

Nina Nevala¹, Irmeli Pehkonen¹, Maarit Virtanen², Anja Tanttu³, Pauliina Mattila-Holappa¹, Pirjo Juvonen-Posti¹,

¹ *Finnish Institute of Occupational Health, Helsinki, Finland*

² *Oulu University of Applied Sciences, Oulu, Finland*

³ *JAMK University of Applied Sciences, Jyväskylä, Finland*

Introduction. Several studies have shown that work accommodation is an effective way of supporting work ability when people return to work, stay at work, or access employment. Accommodations can be designed for the whole workplace or for a single worker due to disability, disease, life situation, or cultural background. **Aim.** The aim of this study was to create an operating model for accommodating work in different occupations. **Methods.** The collaborative development process was carried out with multiprofessional experts and 11 workplaces in the private and public sectors from three parts of Finland. The development of the work accommodation operating model involved several stages. First, we defined the concepts, collected the theoretical frameworks and scientific information, and familiarised ourselves with the earlier operating models. After this, we defined the structure and developed the prototype of the model, using workshops and co-creation. We then piloted, corrected, and released the operating model. Throughout the development process, implementation was supported. The operation model was developed as part of the ESF-funded KUURA project in 2020–2023. **Results.** This operating model is based on the earlier model of the Job Accommodation Network (JAN). It has six phases: 1) identifying the need, 2) collecting knowledge, 3) examining the alternatives, 4) choosing the solutions, 5) implementing the solutions, and 6) monitoring and evaluating. In this model, the actions, roles and responsibilities during each phase at the workplace are defined. To support the implementation of this model, we created a video animation, a guidebook, and a planning formula. **Discussion.** The work accommodation operating model can be adopted nationally in

workplaces, occupational health and rehabilitation services, and occupational education to promote the work ability and employment of working-age people. In the future with the help of implementation research, it would be important to find out the workplace specific functionality.

12-05-2023

13:40 - 15:00 - **Inclusion III - Disability activism and rights** Grand Hotel - Ásgarður /

The Role of Disability Organizations in shaping and implementing the rights of disabled persons: Case-Studies of Austria, Denmark and Germany

Lilit Grigoryan,

Academy for European Human Rights Protection , Cologne , Germany

The Movement "nothing about us without us" caused not only rethinking of disability laws but also achieved new culture of political involvement. At least with the implementation of the EU Directive EC 2000/78 it became clear that national governments cannot avoid the involvement of DPOs in political processes. The UN CRPD set, in its turn, more binding standards for the involvement of DPOs in the law-making processes: The State Parties are obliged to establish all the necessary structural mechanisms to meet the requirements of the UN CRPD, including insuring the DPO participation in all political processes (Art. 4.3 CPRD) by adopting legislation and policies establishing clear, transparent, accessible and effective procedures for consultations at all levels of authority and decision-making. This also applies to monitoring processes (Art. 33.3 CPRD).

The present research shows that the implementation of the Articles 4.3 and 33.3 varies from State Party to State Party. However, the participation and involvement of human-rights-oriented and small organizations of disabled persons, as well as organizations of most vulnerable disabled groups E.G. learning disabled, women, migrants and children do not have access to initial decision-making processes, are excluded from or have limited possibility to express their standpoints during the public hearings. They do not have access to monitoring processes at the administrative level.

To allow the comparative cross-country study and capture the entire implementation effect of the UN CRPD on the political processes and legal application at the multiple governmental levels, the present study was based on the concept of multi-level governance and legal systems. Accordingly, it used the case study approach based on a number of empirical methods such as three-level expert interviews and documentation analysis and applies the most similar systems and most dissimilar systems design.

Effective Participation in the International Monitoring of the CRPD?: The Experience of the Disability Movement from Three Case Studies in Europe

Hanxu Liu,

Faculty of Law, Maastricht University, Maastricht, Netherlands

Organisations of Persons with Disabilities (OPDs) from European countries have a long history of involvement in UN human rights monitoring mechanisms and have significantly influenced the negotiations of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Since the Convention's ratification by the European Union (EU) itself and in its Member States, existing studies paid limited attention to the disability movement's impact on the CRPD's monitoring mandate, although abundant evidence indicated their active input in its State reporting process. This paper addresses this gap by examining the experience and impact of OPDs' participation in the CRPD State reporting procedures in relation to three European State Parties, namely Hungary, Denmark and France, based on empirical research. After introducing theoretical discussions and legal interpretations of the key participatory provisions in the CRPD - Article 4(3) in conjunction with Article 33 - this paper provides a framework for defining, examining and evaluating whether and how OPDs in these countries have achieved effective participation in the UN procedure in alignment with the CRPD's principles. Under this normative framework, the case studies further reveal the significance of State Parties' obligations to establish a robust national structure in facilitating OPDs' effective participation in decision-making processes. This paper concludes by identifying contributing factors and main challenges, as well as putting forward changes needed to realise OPD's right to participate in the international monitoring of the CRPD and maximise their impact in the context of the EU.

Critically assessing terms of engagement between EU institutions of governance and DPOs

Claudia Coveney,

University of Leeds, Leeds, United Kingdom

European structures of governance have proven to be an effective frontier of claims-making for the disabled people's movement. Ratification of the United Nations Convention on the Rights of Persons with Disabilities has solidified the EU's commitment to realising the rights and equality of disabled people in Europe. The UNCRPD, and EU treaties, have served as political opportunity structures for DPOs as they expanded EU competence and secured a position for civil society in participatory democratic politics.

Included in the obligations of the Convention are articles 4(3), and 33(3), stipulating the required involvement of disabled people and their organisations in the development and monitoring of the Convention's implementation.

General Comment 7, provided by the Convention Committee clarifies what can be considered as consultation, involvement and participation, and how to involve disabled people in monitoring of the CRPD implementation. Section 8(3) of the General Comment notes an absence in many cases of meaningful consultation with and involvement of disabled people, through their representative organisations, in the development and implementation of policies and programmes.

EU DPOs organisations have called on the EU in their alternative reports to the UNCRPD to create firmer monitoring processes, independent of the EU institutions, with permanent representation of DPOs and mechanisms to punish non-compliance. The EU's UNCRPD Monitoring Framework has been found to be lacking in civil society reports. The EU institutions' involvement of civil society in policy design remains advisory and ad hoc at many levels.

Using findings from a recent research project undertaken in collaboration with a European DPO, this presentation will examine what kinds of conditions civil society is involved in the UNCRPD's implementation in the EU. In particular, the presentation will critically discuss the concept of 'meaningful consultation' in comparison to the terms of engagement under which recent implementation efforts have been made.

The voices of young, neurodiverse self-advocates on education, diversity and activism in the context of sociopolitical situation in contemporary Poland

Jolanta Rzeznicka-Krupa¹, Sabina Pawlik²

¹ *University of Gdansk, Gdansk, Poland*

² *University of Silesia, Katowice, Poland*

School education seen as a metaphor of society and a laboratory of social life, is not only a process of acquiring knowledge and competences but also a space where young people create their identity, learn interpersonal relationships as well as living together in diverse community. Therefore every time when we think about education we think about the world we want to live.

The main purpose of the presented research is to analyze and reconstruct the voices of teenagers in autistic spectrum (ASD), self-advocates who are engaged in some collectives and activist practices in the field of education. The research questions have been focused on issues like: How do neurodiverse students understand what education is? What experiences create their opinions on Polish educational system? What do they need and expect? What demands and actions do they take to fight for their rights and equal access to education?

The theoretical and methodological framework was constructed interdisciplinary on the borders of educational research and disability studies. The qualitative research was carried out using desk research method, qualitative content analysis and discourse analysis. Data such as texts, posts and audiovisual recordings were collected online, on websites and social media created by young activists' collectives.

The obtained results made it possible to reconstruct the voices and educational experiences of teenager, the ways how students with diverse needs and their parents engage in self-advocacy and activist practices, as well as identify the barriers to equal access to education and postulated changes in the perspective of sociopolitical context in contemporary Poland.

12-05-2023

13:40 - 15:00 - Theoretical understandings and implications from the LIFE-DCY project ÖBÍ 1 Sigtún 42 /

- Moderator: Snæfríður Þóra Egilson, University of Iceland

The intersecting sociocultural mediators of young disabled people's self-understandings of their life quality and participation.

Snæfríður Þóra Egilson,

University of Iceland, Reykjavík, Iceland

The LIFE-DCY research project was directed at the life quality and participation of disabled children and youth in Iceland. The project had two aims a) to evaluate disabled children's quality of life (QoL) as reported by themselves and their parents, and b), to locate commonalities, differences, and conflicting issues in the processes that may influence disabled children's and young people's life quality and participation. Informed by critical and transformative lenses the project's *unpacking phase* consisted of case studies with disabled children and adolescents, and focus groups with young disabled people.

Key findings illuminated the complex web of individual and social structural barriers that produce participation and life quality for disabled children and young people. Access to social spaces, activities, and opportunities typical for children and young people was often limited or simply denied. Thus the young disabled people faced restricted choices that were not necessarily meaningful to them, did not reflect their lifestyle or identity, and undermined the idea of who they wanted to become. The effects of ableism - which portrays impairments as inherently negative and informs social practices that centre and privilege able-bodied norms – were substantial.

The LIFE-DCY research reflects a central challenge for life quality research, recognizing that life quality is not experienced as a stable reality that can be consistently conveyed by children and adults. The same applies to participation as individual wishes regarding involvement and interactions are formed by environmental features such as available opportunities to participate and make meaningful choices, in addition to preferences and state of mind, which vary across time and place.

Social participation of autistic children and adolescents in mainstream schools: Insights from a Bourdieusian lens

Linda Björk Ólafsdóttir, Snæfríður Þóra Egilson

University of Iceland, Reykjavík, Iceland

Background:

Through the application of a Bourdieusian lens, this study aimed to contribute insight into social participation of autistic children and adolescents in mainstream schools in Iceland. The objectives were to a) explore how autistic children and adolescents perceive their social participation in schools, and b) identify structures and processes that facilitate or hinder the children's and adolescents' participation and social inclusion.

Methods:

Thirteen autistic children and adolescents were interviewed about their participation within different subfields of social relations such as the classroom, cafeteria, and playground. The initial inductive analyses drew on Charmaz's constructive grounded theory approach. Then, Bourdieu's theory of practice was applied to critically explore identified categories.

Results:

Four main categories were developed regarding social participation in school 1) Defining and practicing friendships, 2) Dealing with a non-accessible environment, 3) Being bullied, and 4) Experiencing lack of social support. The categories reflected processes and structures influencing the participant's social participation, as well as aspects they considered most important in relation to their possibilities to participate.

Conclusion:

Our findings suggest that more focus needs to be directed to the structure and characteristics of different subfields and how they organize the social participation of autistic young people. And, as emphasized by our participants, it is important to consult with autistic students about what should be done, where and when to ensure that individual needs and wishes are respected and acted on.

Young disabled people paint the town red-Partying and sexual expression; „Let's talk about our party stories“.

Anna Sigrún Ingimarsdóttir, Snæfríður Þóra Egilson

University of Iceland, Reykjavík, Iceland

Background: Partying and the use of alcohol is an example of controversial yet typical social activity among young people. Prior research has shown that although partying may bring risks it can benefit in increased inclusion, community building, belonging, networking, and friendships. More knowledge is needed on how young disabled people make sense of partying and find their place in relation to nightlife. This study attempts to understand young disabled people's experiences of partying by applying the lens of ableism. Central is bringing to light the role partying plays in their lives and how they navigate the hustle and bustle of the party scene.

Method: This was a qualitative study. Data were collected through four focus groups and two individual interviews. Altogether 23 disabled and/or chronically ill people, aged 18-35 took part. Most participants were white and three identified as queer. Constructivist grounded theory was used to categorize and synthesize data.

Findings: Partying was an important means to an end, where participants partied to socialize and find their place. Although partying was usually valued and enjoyed, all participants had experienced conflicting encounters where they were treated as if they were inappropriate or not fit to party. This was complicated to navigate because to gain valued access they had to put up with being stereotyped and harassed.

Conclusion: Overall, partying was considered a positive and socially meaningful activity among the young disabled people. Nevertheless, their access to partying was often complicated or simply hindered because of adultism and ableist assumptions.

Implications of internalised ableism for the health and wellbeing of disabled young people

Ásta Jóhannsdóttir, Snæfríður Þóra Egilson

University of Iceland, Reykjavík, Iceland

When conceptualizing health and wellbeing among disabled people the experience of internalised ableism must be considered. In this paper we argue that internalised ableism is indeed a health and wellbeing issue that materializes by numerous complex psychological, social, and physical consequences. For theoretical grounding we utilise critical disability studies, but also build on feminist theorising about solidarity, and disability activists' concept of "disability justice". We draw on data from focus-group interviews with young disabled people. Whom discussed life quality and wellbeing while reflecting on their childhood and youth, their views on participation in society and what could possibly be a threat to their life quality and wellbeing. Participants consisted of ten men and eleven women, aged 18-35 with different types of impairment. The analysis draws out how internalised ableism has negative effects on the identity, health and wellbeing of the young disabled people who participated. Family support, access to safer spaces, and positive peer interactions are defining factors in how internalised ableism develops, if it is maintained or defied. Peer support and solidarity are strong indicator in promoting healing from internalised ableism. We argue that disability scholars need to address health and wellbeing of disabled people in ableist world.

12-05-2023

13:40 - 15:00 - **Policy and theoretical perspectives V - Supported everyday citizenship** Grand Hotel - Gullteigur B /

"It is true, not a coping strategy": Making analytic space for positive experiences in the everyday citizenship of disability families

Rosemarie Van den Breemer,

VID Specialised University , Oslo, Norway

During my life with a child with multiple disabilities I observed a deep discrepancy between how people perceived us as 'in sorrow', and yet, the richness that my son's life also brought. I felt the weight of a social obligation to have healthy children, or be "miserable" as Wendell (1996, 63) aptly formulated it. Yet, I had a strongly disabled child, but felt often tremendously proud and happy.

Why is it so hard to be believed as a family member when one shares very positive experiences about such everyday life? And why does the scholarly literature likewise reflect such bias?

In this presentation I depart from autobiographical observations about life with a child with multiple disabilities, internal to a postdoctoral participatory action research project. I use these lived experiences as an 'engine' (Hanish 2021, 1) to explore what is referenced in the scholarly literature as an emerging shift from a focus to 'caregiver burden' to 'caregiver benefits' (Green 2007). Such a shift entails an increasing focus on positive family care experiences, instead of mere burdens. But whereas such a transition is well established in the gerontological literature, it is slower to emerge in the scholarship on families with children with multiple disabilities.

In the presentation I explore structural reasons for this delay, going back to deep rooted ideas about disability, imminent tragedy and capitalist productivity (Ferguson, 2001). I argue

that a focus on the positive is emerging. But I also show how a good deal of scholarly work misses target by failing to address the underlying epistemic of the care situation. Focusing on positive experiences “as a form or outcome of coping for parents” (Luijck et al 2019, 184), simply still reconfirms the initial tragedy.

Poetry writing in dementia care as narrative and cultural citizenship

Oddgeir Synnes,

VID Specialised University , Oslo, Norway

The voices of persons living with dementia are rarely heard in society, and when they are, it is predominantly through a tragic narrative of loss of memory, language and identity. Participatory art practices might challenge a one-sided representation of dementia and can open towards nuanced understandings of agency and participation. In this talk, I will present a poetry writing project among persons living with dementia. A close reading of several poems from the project will underscore how lyric poetry with its insistence on the episodic and vertical -- as opposed to narrative's linear and horizontal characteristics -- can preserve first-person perspectives and linguistic capabilities. The practice of poetry writing also opens for validation and affirmation through the potential readings of the poems, both in the poetry writing groups and for a larger audience. Furthermore the project has been presented at a literary festival, at the back of city buses as well as through the publication of a poetry collection. It will be argued that this can strengthen a narrative- and cultural citizenship in the way that the visibility of the poems can open for new forms of strengthening voices and maintaining narrative agency among persons with dementia as well as developing a narrative literacy for the rest of the population.

Using care activities and religious fellowship to support everyday citizenship of people with dementia: Findings from a Nigerian community

Elizabeth Onyedikachi George,

VID Specialised University , Oslo, Norway

Although the number of people living with dementia in Nigeria – and Africa – continues to grow yearly, very little is known about the everyday realities of living with dementia in the country – and on the continent. A review of the literature largely shows an absence of the voices and perspectives of people with dementia in the Nigerian context on how they do everyday life, re-appropriate spaces and resources in their communities, participate in familial and communal activities, and are supported by those around them to continue to lead the lives they want as full members of the family, community, and society. This presentation uses findings from ethnographic fieldwork conducted in a community in southwestern Nigeria and analysed thematically utilising the lens of everyday citizenship to discuss ways that people with dementia in this community are supported by those who live with and around them. Focusing on two main themes: care and religious fellowship, I demonstrate how people in this community use familial and communal care activities – such as visitations from neighbours and friends, food sharing, invitations to events and meetings, supporting the decision to continue to live at home, etc., as well as religious/spiritual support – such as inclusion in communal prayers, pastoral visitations, etc., to support the everyday citizenship of people with dementia.

Exploring citizenship and everyday life through a photo exhibition: a cooperation between adults with intellectual disability, a photographer, bachelor-students and academics at VID Specialized University.

Kirsten Fjetland, Anita Gjermestad

VID Specialised University , Oslo, Norway

In this session we will give a short presentation of the working process of planning and executing the photo exhibition "Various everyday lives". The photo exhibition which was a cooperation between adults with intellectual disability, a photographer, bachelor-students and academics at VID Specialized University.

Photo is an arts-based method which are increasingly used in social research to engage people who might have difficulties, are unable to express themselves or are lacking a voice in the public space. The overall aim of this photo exhibition was to strengthen and give voice to citizenship practises of people living in vulnerable life situations. We also wanted to contribute to illuminate plurality in everyday life for adults who receive health- and welfare services. The photo exhibition itself was a way of creating a space for dialogue and debate between citizens with different everyday life experiences.

In addition, the presentation will elaborate initial analysis and descriptions of what aspects and dimensions of everyday life and citizenship that was highlighted in the various pictures and their related narratives.

12-05-2023

13:40 - 15:00 - **Disability and the lifecourse II - Families** Hilton Nordica meeting room H /

Predictors and characteristics of out-of-home placements in families with MBID

Veronica Baljé, Tessel Sterenborg, Maroesjka Van Nieuwenhuijzen

Expect Jeugd, Amsterdam, Netherlands

Background. Families with mild to borderline intellectual disabilities (MBID) are overrepresented in child protection, and are at higher risk for long and complex family supervision orders (FSOs), including out-of-home placements (OHPs). Research shows that in the Dutch child protection system, the decision to initiate an OHP is not always well substantiated, adequate support is often not available, parents and children are not well-informed and the perspective on reunification often remains unclear. It is important that the process of an OHP is transparent, and that, in principle, efforts are made towards a return home. This is especially important for families with MBID, who need more specialized assistance and benefit from clear and structured information and communication. However, the OHP decision process for families with MBID remains unclear. Additionally, research shows that children of families with MBID are placed out-of-home more often and are reunited with parents less often compared to the general population, but the factors related to this remain unclear. Therefore, this study examines (1) how OHPs are characterized and

(2) which child-, parent-, family- and contextual factors are related to OHPs in Dutch families with and without MBID.

Method. In this casefile study, data of 250 Dutch families with an ended FSO (n=150 with MBID; n=100 non-MBID) are analysed. Chi-square tests are performed to examine the characteristics of OHPs (e.g. course of OHP, received assistance, involvement of parents). Binary logistic regression is performed to study the associations between child factors (e.g. MBID, behavioural- and psychiatric problems and adverse childhood experiences), parental factors (e.g. MBID, mental health and psychiatric problems, substance abuse and traumatic past), family and external factors (e.g. parenting skills, socio-economic status and available network), and an OHP during the FSO.

Results. The data collection is currently ongoing and results will be presented during the conference.

Planning and negotiating social support within the social welfare state: Parental strategies of parents of children with cerebral palsy

Louise Bøttcher¹, Jesper Dammeyer², Camilla Pihl Ramussen³

¹ *Danish School of Education, Copenhagen NV, Denmark*

² *Department of Psychology, Copenhagen, Denmark*

³ *The Elsass Foundation, Charlottenlund, Denmark*

The paper addresses the challenges parents of children with disabilities experience around the time of their child's transition from preschool to school. In the Danish welfare system the social support and school system stresses inclusion as a fundamental value, it is the right of all children with disabilities to receive the necessary support to learn and thrive in order to achieve full participation. Unfortunately, existing research and practice reports document that parents experience the welfare system as an opponent. This is a paradox of the universal social welfare model. The aim of the study was to investigate the strategies parents develop in the interface with the social and educational system.

Twenty-four parents of 15 children with cerebral palsy participated in a mixed methods study combining questionnaires and focus group interviews. The participants were recruited from participants in the course "Godt i gang med læring" [get a good start with learning] at the Elsass Foundation. Results revealed that strategies used to take charge in their meeting with the welfare system and the school system was "providing professionals with knowledge of their child's condition", 'knowing legal rights and using legal arguments', and "networking with professionals and other parents by participation in courses"

Daily life participation among children with and without functional difficulties: a comparative study

Arne Eide¹, Dag Ofstad², Emil Hansen²

¹ *NTNU, Trondheim, Norway*

² *Norwegian National Advisory Unit in Children and Youth (NKBUF), Valnesfjord, Norway*

Children and youth with disabilities face specific barriers to accessing their rights and to obtain full participation alongside their non-disabled peers. To develop interventions in the local community that will promote inclusive societies, we need both baseline data on inclusion and participation as well as innovative approaches to stimulate the local community level, where children and youth live their lives and experience excluding barriers.

In a recent cross-disciplinary and multi-method research and innovation project we aimed at generating in-depth understanding of participation and inclusion in daily life, including home environment, school and leisure, among children and youth with disabilities and utilize this in a service design process with participating municipalities. This presentation concentrates on one element in the study, i.e. measurement and analyses of daily life participation among children and youth.

Four selected municipalities in four different health regions in Norway participated. A questionnaire for measuring participation was developed based on comprehensive Focus Group Discussions with parents, youth and service providers and previously published attempts to measure participation. The survey in the four municipalities included 186 children, youth and young adults through a combined sampling strategy. The questionnaire measured four different dimensions of perceived participation, i.e. assessment of participation frequency, comparison with peers, satisfaction and barriers. Results showed that children and youth with functional difficulties scored higher than children and youth without functional difficulties on barriers for participation but lower on the other three participation dimensions. Differences between the four contexts were relatively small. Still, further analyses aim to reveal whether known socio-economic and structural differences in the municipalities contribute to explain some of the variation in participation.

Caring or being cared for ? The care relationships of middle-aged people with learning disabilities in two-generation elderly Families

Hui-Yu Kuo,

National Chung-Cheng University, Chiayi County, Taiwan

Despite the growing interest in the care relationships of two-generation elderly families, little is known about the experiences of people with learning disabilities in care relationships from their perspectives. The research aims to explore the experiences of middle-aged people with learning disabilities in care relationships. The methodology adopted is qualitative approach, with semi-structure interviews being conducting with 20 middle-aged people with learning disabilities. The research explores the experiences of people with learning disabilities in receiving and giving care , and how people with learning disabilities develop reciprocal relationships with their aging parents. People with learning disabilities are often portrayed as passive, powerless and dependent persons who need to be cared for. The research challenges such stereotypical view of people with learning disabilities. People with learning disabilities are not persons who are always being cared for, in some cases they have to take care of their aging parents. They may also need support to look after their aging parents. The research findings show the interdependency in care relationships between people with learning disabilities and aging parents. The research may provide insight into policy making and disability services to support two-generation elderly families in Taiwan.

12-05-2023

13:40 - 15:00 - **Childhood disability III - Parents of disabled children**
Hilton Nordica meeting room F /

The centrality of work and meaning in life among parents of children with and without disabilities aged 0-12.

Maayan Fine¹, Limor Gadot²

¹ *Ben Gurion University, Beer Sheva, Israel*

² *Sapir Academic College, Sderot, Israel*

The number of disabled children in Israel is approximately 269,000. Thus, many parents are categorized as parents of disabled children. In a person's life, work plays a central role and influences his perception of meaning. It is possible that parents of children with disabilities experience a different balance between work and home demands, so the centrality of work, and meaning in life can be different from that of parents of children without disabilities.

Objective: To analyze the differences between parents of children with disabilities and parents of children without disabilities on the variables Meaning in life and Centrality of Work

Participants: 167 parents. 79 parents of children with disabilities, ages 0-12, who speak Hebrew. Control group: 88 parents of children without disabilities, ages 0-12, who speak Hebrew.

Procedure: An initial cross-sectional study was conducted during 2022. Sampling method Snowball/convenience sampling, research participants answer an online questionnaire on social networks.

Findings: The findings indicate a distinct difference in the meaning of life of parents of children with disabilities ($M = 4.81$, $SD = 1.26$) compared to parents of children without disabilities ($M = 4.88$, $SD = 0.82$). Parents of children without disabilities experience more significant meaning in life than parents of children with disabilities. Another distinct difference in the centrality of work in the life of parents of children with disabilities ($M = 3.71$, $SD = 0.96$) compared to parents of children without disabilities ($M = 3.87$, $SD = 0.5$). Parents of children without disabilities experience a more significant centrality of work in life.

Discussion: The findings shed light on work-home balances and priorities. Caring for a child with disability at an early age may maintain a mutual influence on both the centrality of the work and, as a direct consequence, on the sense of the meaning of parents with disabled children. Implication for policy will be discussed.

Being 'mum': becoming in conversation

Sharon Smith,

University of Birmingham, Birmingham, United Kingdom

This presentation discusses a postqualitative inquiry where both the theory and method stem from my experiences as a parent of a disabled child.

There is a plethora of research about disabled children and their families that identifies a 'host of subject positions occupied by parents and/or mothers: fighting parents, disabling parents, tragic parents, empowering parents' that fails to recognise that parents defy categorisation (Goodley, 2007:146). In contrast, this inquiry recognises that 'the process of becoming – or not yet being – forms an essential part of parents' engagement with and resistance to a whole host of disability knowledges' (Goodley, 2007:146).

The research approach draws on Blanchot's conception of conversation as 'plural speech' (Blanchot, 1993). This form of conversation does not seek to 'annex the other' or study them 'as a thing', instead it is conditioned by 'a relation of infinity and strangeness' (Bojesen, 2019:653). The aim of using conversation is not 'to synthesise contradicting thoughts or ideas, to reach consensus, to prove a hypothesis or to generate truths' about parents or inclusion, rather it is 'more likely to reflect the qualities of talking with friends: it is discontinuous, proliferative, disorganised' (Harrison et al, 2020:408).

I will discuss how seven parents of disabled children were engaged in individual ongoing conversations with me. Each parent was invited to start our 'conversation' by bringing a photo, document, or any object they considered a prompt, to start a discussion about their role as a parent of a disabled child and/or their child's inclusion. Every conversation took a different shape in terms of frequency, mode and the topics discussed, responding to participants' interests. These ongoing conversations allowed an exploration of uncertainty, contradictions, and tensions, through which it becomes possible to think differently about parental subjectivity and parents' approaches to their disabled child's inclusion in education.

'Empowered but alone'? A systematic integrative review on the responsabilization of early autism caregiving practices among parents in Sweden and Canada

Hailey Rheault,

Örebro University, Örebro, Sweden

Background: The aim of this integrative review is to identify and analyze the process of learning about and caring for young children with 'autism spectrum disorder' (ASD) experienced by parents in Sweden and Canada. Although the countries differ in terms of how they institutionally support respective families, they both exhibit disability policies and practices which ideologically empower parents to take the lead in caring for their children with ASD. In light of the process of responsabilization, this paper critically analyzes the ways in which current studies frame parental involvement in early ASD caregiving in both countries.

Method: 31 peer-reviewed, qualitative papers published in well-established and recognized journals between 2012-2022 were identified from electronic database searches (Social Science Premium Collection and SwePub) conducted in Sweden (n = 7) and Canada (n = 24).

Results: Three topics were identified through a critical interpretive synthesis of the texts. Specifically, parents were depicted as (dis)similarly experiencing (1) ambiguities in allocating services, (2) the need to become lay experts on their children's ASD, and (3) difficulties in reconciling their other work and family responsibilities alongside early ASD caregiving practices.

Preliminary conclusion (drafted): In terms of parental involvement in early ASD caregiving, the examined studies in Sweden indicated that parents were implicitly empowered to become leaders in lieu of cohesive guidance and support from professionals; meanwhile, parents were described as being explicitly directed to perform certain roles during ASD interventions in coordination with professionals in Canada. In light of such contexts for ASD caregiving, the paper addresses the need for further studies to examine the potential social, gender, and economic implications of responsabilizing parents as purveyors of early services on behalf of their children's needs.

Balancing Care and Work When Caring for a Disabled Child

Kaja Østerud¹, Cecilie Anvik², Elena Albertini Fröh³

¹ *Norwegian Social Research, OsloMet, Oslo, Norway*

² *Nord Universitet, Bodø, Norway*

³ *Oslo Metropolitan University, Oslo, Norway*

According to quantitative research on parents, having a disabled or chronically sick child reduces mothers' working hours, income and labour market participation and increases long-term sickness absence (Brekke & Nadim, 2016; Reisel et al., 2020; Wondemu et al., 2022). But how is this apparent conflict experienced, and how does it play out in practice?

This article investigates how caring for a disabled child impacts the participation in paid work. We use a data set following a multiple case study design. We followed 12 families with disabled children over a period of approximately a year. We interviewed the parents on multiple occasions and observed interprofessional meetings concerning the child. In addition, we got permission to interview the family's municipal coordinator, who is responsible for coordinating the support the family receives.

The findings show how the parents, and in particular the mothers, report considerable conflict between care and participation in paid work. This is partially the intensified direct care the child needs, but the families also report considerable effort needed towards fighting the system to get the services and benefits they need. The parents talk about conflict with the workplace and derailed careers. Some of the mothers have left the labour market completely. However, a few of the parents demonstrate how their care work has resulted in certain strengthened competencies, which they have used as an asset in their search for new career paths.

12-05-2023

13:40 - 15:00 - **Childhood disability II - Leisure and culture** Hilton Nordica meeting room D /

Examining Children With Disabilities' Right to Leisure: The Case of the 'Calm Room' in a Separate Leisure Space

Rebecka Tiefenbacher,

Linköping university, Linköping, Sweden

Research has distinguished between three ways of organizing leisure for children with disabilities: mainstream, inclusive and separate provision (e.g., Hodge and Runswick-Cole 2013). The right to the latter is stipulated in the CRPD, which states that 'States Parties shall take appropriate measures [...] to ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities' (art. 30). Little is known, however, about separate leisure provisions for children with disabilities, such as how they are organized, what children's perceptions of these are, or what children do there.

In this presentation, I will share insights from an ethnographic study of a separate leisure space aimed at children between the ages of 3-11 with disabilities such as ADHD and ASD, focusing specifically on the 'calm room' in the facility. The purpose of this room is to provide a place for calm and stillness, particularly as a way of preventing or handling outbursts. Through interviews with key informants at the leisure space, me and the project PI learned of the original intentions and ideas behind the calm room. However, these interviews, as well as the ethnographic study of the children's activities in the leisure space, have also revealed that the room is most often not used by the children in the way that the adults initially intended. This, I suggest, demonstrates a tension between the room as a 'place for children' and the room as a 'children's place'. In the presentation, I will talk about these tensions and what they can tell us about children's points of views of separate leisure provision.

References

Hodge, Nick, and Katherine Runswick-Cole. 2013. "“They Never Pass Me the Ball”: Exposing Ableism through the Leisure Experiences of Disabled Children, Young People and Their Families." *Children's Geographies* 11 (3): 311–325. doi:10.1080/14733285.2013.812275.

Can separate leisure be inclusive?

Cecilia Lindgren,

Linköping University, Linköping, Sweden

The UN Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities state that disabled children have the right to leisure and recreation that allows for social integration and individual development. What does that mean and how can it be achieved? In a Swedish context, follow-ups show major shortcomings in this area. Specifically, children with neuropsychiatric disabilities such as ASD, ADHD or Tourettes syndrome find it difficult to establish meaningful leisure time (Swedish Agency for Participation 2014). In an ongoing research project we examine how the right to leisure is implemented in practice at an YMCA leisure centre aimed at this group of children (3-11 years of age) and their families. In previous disability research, leisure activities are characterized as mainstream, inclusive or separate, and even though exclusion from mainstream leisure is a fundamental problem, it is also questioned whether inclusion is always preferable to special provision (Hodge & Runswick-Cole 2013). Separate leisure settings can serve as sites for empowerment, away from the ableist gaze. The conference presentation is based on a qualitative analysis of interviews with parents visiting the leisure centre with their young children. It focuses on parents' reasoning about the value as well as the dangers of separate leisure spaces and highlights the experience of needing an

'unordinary' place to pass as an 'ordinary' family, but also the commitment to not hiding away but making diversity visible.

References:

Hodge & Runswick-Cole (2013) 'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families, *Children's Geographies*, 11:3, 311-325.

Swedish Agency for Participation, Report 2014:4

KidsAction coaching approach for an adapted physical activity in a ski lesson context

Lise Olsen¹, Mojgan Gitimoghaddam², Stephanie Glegg², Veronica Connors³, Kathryn Campbell⁴, Jenny Hawes⁵, Tara Nault⁶, Bill McKellin⁷, Amanda Field⁸, Jean Paul Collet⁸

¹ University of British Columbia Okanagan, Kelowna , Canada

² University of British Columbia, Vancouver , Canada

³ Adaptive Sports at Sun Peaks , Sun Peaks , Canada

⁴ Adaptive Sports Sun Peaks , Sun Peaks , Canada

⁵ Adaptive Sports Sun Peaks , Sun Peaks, Canada

⁶ Indigenous Sport Physical Activity Recreation Council, Victoria, Canada

⁷ University of British Columbia, Vancouver, Canada

⁸ University of British Columbia , ,

Introduction: KidsAction is an evidence-based coaching approach designed to assist children with neurodevelopmental and other disabilities to engage in physical activity and to help their families feel supported. The approach uses personalized, goal-directed coaching and includes a suite of online resources and strategies to assist physical activity instructors and families to foster physical literacy, inclusion, and Indigenous cultural safety through physical activity that matches each child's abilities and interests. We have adapted the KidsAction materials for those participating in an adaptive ski program in British Columbia, Canada.

Methods: We have worked collaboratively with adaptive ski program managers and coaches to design KidsAction implementation and evaluation strategies to fit with the program activities and needs. This included adapting tools to suit activities and methods of instruction taking place in an adaptive ski lesson context. We have also assisted with organizing family networking activities during children's ski lessons and have developed evaluation and data collection strategies tailored to the adaptive ski program needs and preferences.

Results: We will present on the ways that program implementation and evaluation plans were tailored to suit the adaptive ski program. This will include presentation of tools and methods used, as well as summary data collected in terms of child and coach participation in KidsAction. We will include results of interview data from adaptive ski coaches regarding barriers and facilitators to using KidsAction and suggestions for refinement.

Discussion: With flexibility built in, the KidsAction approach can be used in a variety of settings. Our team uses evidence, theory and tools from the field of implementation science to guide co-development of implementation and evaluation plans to inform tailoring of KidsAction strategies to each site. Our goal is to ensure more children and families have

access to effective, culturally safe, and inclusive physical activity programs wherever they live.

Exploring Child-Driven Culture from the Perspectives of Disabled Youth

Shanon Phelan¹, Kassi Boyd², David McConnell²

¹ *Dalhousie University, Halifax, Canada*

² *University of Alberta, Edmonton, Canada*

Full inclusion for disabled children and youth necessitates an understanding of *child-driven* culture, culture produced by and between children, for children, without the mediation of adults. Adult-directed inclusion initiatives, like those in education and leisure settings, do little to cultivate inclusion in child-driven culture. When disabled youth are excluded from child-driven culture, they are also excluded from opportunities to participate in different types of play, social, and physical activities, resulting in negative physical, psychological, and socio-emotional health and well-being outcomes. Gaining insights into inclusion in child-driven culture for disabled youth is critical for promoting health, well-being, and inclusion in all aspects of community and cultural life.

The primary objective of this participatory research was to explore child-driven culture from disabled youth's perspectives. Disabled youth were invited as co-researchers to set the research agenda, refine the research question, create data generation plans, generate data, and participate in sense-making of the data. The youth identified the research question: *What is it like to be a teen from teens' perspectives?* Data were collected using a variety of methods including focus groups, youth-generated texts, youth-driven interviews, and follow-up interviews with researchers. We drew on reflexive thematic analysis to generate themes: (1) staying on pace and in the know, (2) for the sake of belonging, (3) being a teen is complicated, and (4) clashing priorities. A novel finding from this study was the illumination of the ways youth curate child culture *for* adults.

Child-driven culture is made up of a unique set of evolving languages, practices, values, technologies, and meaning-making processes. Engaging in, and contributing to, the (re)production of child-driven culture is central to inclusion and a felt sense of belonging in childhood. Findings have the potential to inform the ways we re-envision and enact inclusion in policies and practices.

12-05-2023

13:40 - 15:00 - **Education II - Professionals' perspectives** Grand Hotel
- Muninn /

Gauging the impact of social model awareness among K-12 teachers seeking to adopt inclusive practices

Frederic Fovet,

Thompson Rivers University, Kelowna, Canada

There has been an exponential development – if not an explosion - of inclusive policies and practices adopted within the elementary and secondary sectors in most Global North jurisdictions over the last two decades. While the discourse around inclusion has grown as a result, it would be unwise to assume that inclusive practices have become the norm or that they have been seamlessly integrated: there is still a lot of tension and unease among teachers seeking to implement inclusive practices; this translates into hesitation and sometimes even a push back from school leaders; there remains much confusion at times as to the intentions and theoretical principles that ground these efforts.

The session will offer insights into a study which sought to determine to what extent an introduction to the Social Model of Disability was effective and impactful in allowing elementary and secondary school teachers to ground their work in the field of inclusive practices with conceptual clarity. It is argued that this has so far been the missing piece in pre-service teacher training as well as in-service professional development. The inclusion discourse within the primary and secondary landscape, both in terms of policy documents and field resources, has not explicitly or effectively integrated Disability Studies - and more specifically the Social Model of Disability - when framing and formulating inclusive provisions. As a result, teachers' theoretical understanding of the foundations for inclusive reforms as they relate to the rights of children with disabilities is shaky at best and this affects these classroom professionals' commitment to broad transformative pedagogical reforms. Bio-medical and deficit models prevail, and other lenses and constructs offered by the Disability Studies literature remain absent from this professional reflection.

The session explores qualitative data collected among K-12 teachers as they were being introduced to the key features of the social model of disability. The data analysis gauges to what extent this transformed their views on inclusion in the classroom.

This fully interactive session will lead the participants, in a hands-on fashion, along the journey experienced by these teachers and allow for an experiential understanding of the degree to which any material developing awareness of the social model of disability can have immediate impact on the clarity and effectiveness of inclusion efforts in the primary and secondary sectors. More widely, a discussion will be triggered in the session around the urgency of including Disability Studies scholarship in pre-service teacher training.

Does rehabilitation enable inclusive participation in educational settings for children with disabilities?

Annastiina Vesterinen¹, Anu Kippola-Pääkkönen², Anu Kinnunen², Maarit Karhula³,

¹ *South- Eastern Finland University of Applied Sciences, Mikkeli, Finland*

² *Lapland University of Applied Science, Rovaniemi, Finland*

³ *Research at Kela The Social Insurance Institute of Finland, Mikkeli, Finland*

The aim of rehabilitation is to enable children's development and functioning in educational settings. Rehabilitation should support education professionals to implement inclusive practices so that children with intellectual and developmental disabilities have equal possibilities to participate and learn. Research has not enough focused on collaboration contributing to achieve this goal.

This study aimed at describing the collaboration between families, professionals and therapists, as well as the perceived outcomes of rehabilitation. The study concentrated on answering the following questions: How do these participants collaborate in planning and

implementing rehabilitation? How does rehabilitation affect the learning and participation of children with disabilities in educational settings?

The study was a mixed methods study. Parents' perspectives were studied through a survey (n=244) and interviews (n=16). Therapists' perspectives were gathered through a survey (n= 309), and education professionals (n= 17 groups) were interviewed in focus groups. The survey data were analysed statistically and interview data through thematic analysis. These different data sets were then grouped by research questions.

Collaboration is a complex phenomenon influenced by the individual characteristics of therapists, education professionals, parents, as well as organisational cultures and working practices. The study showed that interprofessional collaboration between education professionals and therapists took mostly place as information exchange, and therapy was often separated from everyday activities. Working, reflecting, and solving problems together was clearly less common. The perceived outcomes of therapy typically related to promoting interaction, communication skills and developing everyday activities of children with disabilities.

The study showed that to support children's equal participation and inclusion in different educational settings, collaboration should be understood more broadly and carried out together. This requires development at different levels: individual, organisational and societal.

keywords: rehabilitation, children with disabilities, parents, professionals, inclusion, collaboration

Educating for inclusion: Teaching Design for all in the wild as a motivator

Kjetil Falkenberg¹, Lars Oestreicher²

¹ *KTH Royal Institute of Technology, STOCKHOLM, Sweden*

² *Uppsala University, Uppsala, Sweden*

There is a strong relationship between the computer science topics universities teach and the newly introduced nationwide EU legislation on accessibility. The demand for employable experts is expected to be higher than the universities can handle, risking that we graduate students lacking the competence needed to deliver accessible solutions at the level required by law. To assess the extent of accessibility education in our universities (KTH Royal Institute of Technology and Uppsala University at the Faculty of Science and Technology), we set out to identify courses that in their descriptions list skills relevant to a career involving designing for all. The results are unsettling: KTH has 2,055 undergrad courses but only one is devoted to accessibility. Similarly, at Uppsala University there is also only one selectable course directly targeting this subject for engineers and computer scientists as non-excluding design. In social and medical sciences there are a few additional courses, but not aimed at our target group of students. Furthermore, at KTH fifteen courses included accessibility in some aspect, but less than one in twenty students take these courses. In Uppsala, the topic is introduced through one or two guest lectures in a few courses aimed at computer scientists. In the continued study presented here, we interviewed 20 students of computer science at Uppsala University and KTH to identify driving factors and barriers for choosing courses teaching accessibility skills. One assumption we set out to test was whether teaching in real-life settings and exposing student projects in public spaces such as museums would increase motivation and influence course selection. We argue that

accessibility education must be integrated into all university programs and that these particular skills must be searchable by interested students. To increase impact and raise awareness, we encourage exposing design for all in public settings.

Is there Space for Dyslexic Pupils in High Attainment Educational Environments? Evidence from the Millennium Cohort Study into Attainment Grouping in UK Primary Schools.

Esther Outram ,

Durham University , Durham , United Kingdom

Despite policies designed to include and support dyslexic pupils within mainstream schools in the UK, dyslexic pupils continue to report lower levels of academic self-concept and to achieve poorer exam results compared to their non-dyslexic peers. This research examines whether these disparities are exacerbated by grouping pupils by 'ability' for instructional purposes, a practice that has become widespread throughout the UK's nominally comprehensive primary school system. Drawing on data from the Millennium Cohort Study (N=3,510), the research asks: i) whether dyslexic pupils are underrepresented in English and maths high attainment groups in UK primary schools, both before and after controlling statistically for test scores at age 7 alongside sex and social class background, and ii) whether teachers underestimate the ability of dyslexic pupils relative to their test scores in ways that inform 'ability group' allocation. Findings show that dyslexic pupils are underrepresented in high attainment groups for English and maths (age 7 and 11) and teachers' perceptions of pupils' ability impacts allocation over and above the impact of test scores. This research is the first to include dyslexia in the discussion of the social justice of attainment grouping and contribute to the discussion about the educational spaces dyslexic pupils occupy in an 'inclusive' system; thus, questioning the appropriateness of attainment grouping in primary schools.

12-05-2023

**13:40 - 15:00 - Human rights II - Disability and violence:
Phenomenon and violence experienced by persons with disabilities
Grand Hotel - Hvammur /**

Pleasure-shame and disability: The impact of microaggression on gender identity and the expression of sexuality in disabled people's lives

Embla Guðrúnardóttir Ágútsdóttir, Ásta Jóhannsdóttir

Háskóli Íslands, Reykjavík , Iceland

The aim of this paper is to explore disabled people's experiences of expressing their sexuality and the reaction such expressions stir. Furthermore, we investigate how disabled people experience their bodies as sexual and the impact of microaggressions on their gender identity. The data was collected between 2019 and 2021 and consists of five interviews and three focus group meetings.

Current studies on microaggression and the sexuality of disabled people are few, and thus it is vital to shed light on their experiences. The experience of marginal groups is often coloured by microaggression that is not very visible and regularly trivialised. International studies have shown that microaggression is a dominant factor in the daily lives of disabled people and thus important to examine further.

Early findings of our research shows that microaggression is a leading factor in disabled people's daily lives and that it requires constant reaction. One of the manifestations of microaggression is the idea that disabled people are infantilized or seen as asexual. The message that participants receive is that they should be grateful to have a partner thus they have little room to make demands or set boundaries. When expressing their sexuality, it is often accompanied with the feeling of shame.

How can we better prevent and combat violence against persons with disabilities?

Maria Melin¹, Maria Montefusco²

¹ *Swedish Agency for participation , Sundbyberg, Sweden*

² *The Swedish Agency for Participation, Sundbyberg, Sweden*

In 2021, the national Agency for participation (MFD) was commissioned by the Swedish government to investigate the prevalence of violence against persons with disabilities in Sweden. MFD was also to map knowledge and support measures that are available for professionals who meet persons with disabilities who have, or might have been exposed to violence or that are at risk, and how this knowledge and support measures are used. MFD was also to map knowledge gaps and give recommendations on how to meet the needs of the target groups and suggest future research projects. The investigation is framed by the intentions and goals of the Swedish government's national strategy for stopping and preventing men's violence against women. A report on the final results and recommendations is published in January 2023.

Aim: map and provide an overview of available knowledge about disability related violence, support measures and recommendations on measures to better meet the needs of persons with disabilities who have been, are being or are at risk at being subjected to violence.

Methods: multi method approach, mapping available statistical resources in population-based data, research and other knowledge. During the investigation, quantitative and qualitative studies have been carried out with several target groups and stake-holders on all levels of the Swedish welfare state system. Active dialogues have taken place continuously with stake holders representing persons with disabilities.

Results: (in process)

Conclusions: (in process)

Keywords: violence, disability, violence prevention, victim support etc (in process)

Increased risk of childhood violence exposure among individuals with disabilities in Sweden

Steven Lucas,

Uppsala universitet, Uppsala, Sweden

Background: Previous research has shown that violence disproportionately affects people with disabilities, and this population is more vulnerable to severe violence victimization than others.

Aim: To evaluate the prevalence of physical, emotional and sexual violence during childhood among individuals with self-reported disabilities compared to non-disabled individuals in Sweden.

Methods: A random, population-based sample of 10 000 women and 10 000 men aged 18-74 living in Sweden were invited to participate in a survey concerning violence exposure and current health and health-related behaviors. Statistics Sweden conducted the survey in the spring of 2012, and 10 373 individuals responded in total, giving a response rate of 52%. The questionnaire included detailed items to assess exposure to sexual, physical or psychological violence before the age of 15, between 15-17 years of age and in adulthood. Two questions were included to assess disabilities among the respondents. The data were analyzed using descriptive statistics and multivariate logistic regression.

Results: Respondents with disabilities that were present during childhood reported experiencing severe forms of sexual violence (21%), physical violence (29%) and psychological violence (27%) to a greater extent than those without disabilities (11%, 14% and 11%, respectively). These differences were especially evident among women. When different types of disabilities were analyzed separately, individuals with psychological/cognitive disabilities had the highest risk of exposure to severe sexual (OR 3.6), physical (OR 4.9) and psychological (OR 6.8) abuse compared to individuals without disabilities.

Conclusions: In this population-based sample, individuals with self-reported disabilities in childhood were at significantly greater risk of severe sexual, physical and psychological abuse before the age of 18. The results indicate the need for further preventive efforts to protect children with disabilities from all forms of violence.

Violence against children with disabilities, what do we know?

Carl Göran Svedin ,

Marie Cederschiöld högskola, Sköndal, Sweden

Background: Violence in various forms against children with disabilities has been found to be a fairly unexplored area in general but also in Sweden.

Aim: To evaluate the childhood prevalence of psychological, physical, and sexual abuse, sexual exploitation and bullying among adolescents with self-reported disabilities compared to non-disabled adolescents in Sweden.

Methods: A nationally representative sample of 3,268 students in the third year of high school (18 years of age) answered an anonymously questionnaire which gives captures experiences of various forms of childhood maltreatment. The material was collected between December 2019 and March 2021.

Results: The study shows that disability almost doubled the likelihood of having been bullied, psychologically abused, physically abused, or subjected to sexual abuse. It more than doubled the risk of having been subjected to sexual exploitation. Adolescents with neuropsychiatric or psychiatric conditions were particularly vulnerable. Adolescents with multiple disabilities were more often exposed to psychologic abuse, bullying, physical abuse, and sexual abuse compared to adolescents without disabilities or with only one disability. The adolescents with some form of disability were more often exposed to two or more types of violence and abuse - multiple exposure. They also had significantly worse mental health than adolescents without ant disability. With several different types of disabilities, ill health increased. Adolescents who had been exposed to some form of violence generally had worse mental health than those who had not and students with a disability health was further deteriorated. In this regard, one can speak of a double risk for mental illness when traumatic events are added to the disability.

Conclusions: Children and young people with disabilities have the same rights as all other children, but the scant Swedish research available in the area indicates that this group's special vulnerability to violence and abuse has not yet received enough attention. Prevalence studies are an important starting point for understanding the extent of the problem and for tailoring necessary interventions.

12-05-2023

13:40 - 15:00 - **Rehabilitation, technology and accessibility II - Universal Design** Grand Hotel - Setrið /

- Moderator: Thomas Skovgaard , SDU

Invitation to think and do Universal Design in practice.

Leif Olsen¹, Anne Kathrine Frandsen², Inge Bonfils³,

¹ *VIVE - Det Nationale Forsknings- og Analysecenter for Velfærd, København K, Denmark*

² *Aalborg University, Copenhagen, Denmark*

³ *KP, University College Copenhagen, Copenhagen, Denmark*

In this presentation, we unfold the background for the initiative to write a Danish anthology about the important and big challenges related to transform the values and vision in Universal Design into practice. We also present the anthology as it turned out to become reality in a book with 13 chapters focusing on topics such as: housing, design of products, digital accessibility, design of jobs, sensitivity to design, critical questions for universal design, creative norms, teaching, person-environment-occupation model and interdisciplinary cooperation.

Initially we invited our colleagues to contribute with chapters, which was relevant for the topic but also made through collaborative interdisciplinary processes within the network

UniversalDesignHub, supported and hosted by the Beveca Foundation in Denmark. Many ideas and suggestions for relevant and interesting chapters was made and the requirement to write the chapters in groups and through interdisciplinary collaboration was accepted as an relevant challenge and necessity create new solid knowledge to push or the goal and transform Universal Design from vision to reality.

Promoting an inclusive mindset at a technical university through pedagogical design tools

Dagny Valgeirsdottir, John Paulin Hansen,

DTU, Lyngby, Denmark

This presentation describes a research-in-progress project that is part of an initiative at DTU Skylab called Technology leaving no one behind. The initiative aims to provide opportunities and support to make universal design thinking a natural part of engineering new sustainable technological solutions at the Technical University of Denmark. As part of the initiative a Universal Design Playbook was developed which aims at supporting its users to organize and prepare for hosting design processes and co-creative workshops, with an additional layer of inclusivity tips and reminders. The Universal Design Playbook is an online design guide which was user tested for its intuitiveness and usefulness as well as how well it served as a reminder to think inclusively in a workshop setting.

The contents of the Universal Design Playbook have furthermore been applied as pedagogical tools in courses across the technical university with the purpose of promoting an inclusive mindset as widely as possible. In addition to the application of the Universal Design Playbook in curricular activities it has been utilized in a variety of other settings such as various extracurricular activities, entrepreneurship initiatives, faculty events as well as with industry partners.

Residential architecture – how state power becomes visible in institutions for people with disability

Inge Bonfils¹, Anne Kathrine Frandsen²,

¹ *KP, University College Copenhagen, København K, Denmark*

² *Aalborg University, København K, Denmark*

This presentation combines insight from historical studies of the development of institutions for people with intellectual disabilities (ID) in Denmark, with research into residential architecture. Drawing on Foucault's notion of power as embodied in discourse, knowledge and 'regimes of truth' (Sandmo, 1999) we show how state power becomes 'visible' in the location, building and interior design of institutions.

Historically, Denmark has a long tradition of building large institutions for people with ID, ranging back to the second half of the 19th century (Kragh et al., 2015). This era of institution lasted until the 1970th. Institutional architecture resonates with the state's power: People with ID were considered deviant and needed medical treatment. Institutions for people with ID were placed in rural areas, with fresh air and access to parks and nature, in line with other kinds of healthcare buildings (Ejlers, 1994).

During the 1950th a growing public critique was raised against the treatment of people with ID and the residential institutions. Families of people with ID and leading figures in social policy united to oppose the inhuman treatment and inappropriate living conditions that people with ID were met with in the institutions (Bengtsson & Kristensen, 2006). This led to a change in social policy towards equal opportunities in terms of residential facilities for people with ID. Since the 1970s institutions have been rebuilt and replaced by smaller residential facilities. Residential facilities were now seen as a home. New institutions were built in line with typical family homes, and today we see new types of apartment buildings that comprise institutions for people with ID that are very similar to residential multi-storey housing.

We conclude that the changes in the design of residential facilities for people with ID have been part of the struggle for equal opportunities and human rights.

Universal job design

Thomas Bredgaard¹, Kristian Moltke Martiny²,

¹ *Aalborg University, Aalborg, Denmark*

² *Enact:lab, København K, Denmark*

In this presentation, we will examine what it means to transfer and apply the concept of universal design to the Danish labor market. We present a new concept that we call "universal job design". Universal job design is inspired by the principles and goals of universal design and is about designing workplaces and jobs so that they are accessible and inclusive to everyone regardless of functional ability. This means that the focus shifts from compensation and workplace adjustment to prevention and diversity. Universal job design may contribute to increasing employment for people with disabilities and create a more diverse labor market.

In the presentation, we will present the findings from a review of the limited literature on universal design and workplaces. Then, based on the literature, we identify a definition of the concept of "universal job design" and discuss the challenges and potentials in the application of the concept of universal job design in the labor market.

Perspectives for interdisciplinary cooperation and collaboration to transform the vision of Universal Design into practice

Inge Bonfils¹, Anne Kathrine Frandsen², Leif Olsen³,

¹ *KP, University College Copenhagen, København K, Denmark*

² *Aalborg University, København K, Denmark*

³ *VIVE - Det Nationale Forsknings- og Analysecenter for Velfærd, København K, Denmark*

In this presentation, we first unfold some of the main points made in the new Danish anthology about the important and big challenges related to transform the values and vision in Universal Design into practice. Second, we present and discuss how the different contributions deliver new perspectives for the future development of universal design in both as ways of thinking about design and ways of turning the values and visions in universal design into practice.

Some of the main perspectives in the search for new ideas and knowledge to push for universal design into practice are e.g. the interplay between material structures and social life, the interplay between design and the view of human nature, critical aspects of universal design and important aspects of interdisciplinary cooperation and collaboration.

12-05-2023

13:40 - 15:00 - **Health II - Theoretical, ethical and policy aspects**
Hilton Nordica - Meeting Room G

There is a need to rethink cancer survivorship. How can disability studies inform knowledge expansion?

Eva-Mari Andersen,

Department of special needs education, Oslo, Norway

Broadly, the often-used academic term cancer survivorship refers to being cured of cancer. However, the term's definition, functionality, and relevance are debated. Made visible when reviewing research on cancer survivorship are some decisive points: The survivorship discourse has been created for purposes of treatment and care, in addition to medical and professional progress. As such, the survivorship discourse is dominated by biomedical objectives. In this, the personal experience of cancer survival is sidelined. When encouraged to voice their experiences, cancer survivors emphasize the disjunction and discordance between lived life, medical descriptions and concerns, and the cultural and social expectations related to what it means to survive. This paper will focus on exploring results from an ongoing qualitative research project on narratives of young cancer survival. Informed by disability studies, the project explores cancer survivorship as being - having bodily, personal, relational, social, cultural, and political manifestations. In the project, cancer survivorship is addressed through repeated semi-structured to unstructured interviews and analysis through a co-constructed grounded theory approach – of which both participants and the researcher have survived cancer at a young age. Based on this, the paper that will be presented intends to make visible emerging narrative threads from the project and to elaborate and discuss them with means of disability studies. As such, the paper will touch on the intersecting topics of health, disease, chronic illness, and disability. Lastly, the paper aims to initiate discussions on the relevance and necessity of disability studies when exploring cancer survivorship.

Applied Behaviour Analysis: What is a good or bad behaviour for people with intellectual disabilities and who should decide?

Øyvind Snipstad ,

Inland Norway University of Applied Sciences, Gjøvik, Norway

This presentation builds on a paper about ethical concerns regarding the application of Applied behavioural analysis (ABA) on people with intellectual disability.

ABA is both a pedagogic and therapeutic method, where the intention is to alter unwanted or unhealthy behaviour that a person exhibits. ABA is a common approach among social workers who are working with people with intellectual disability. Drawing on behaviourism, ABA identifies itself in line with natural science and claims that altering behaviour as well as defining what kinds of behaviour are *desirable* and not can be accomplished in the same objective and neutral manner as when studying other non-human objects. This standpoint poses some fundamental ethical questions related to how certain social conditions, behaviour, kind of expressions should be chosen over another. Thus, the focus in this presentation is not concerned with how this method is conducted *per se*. Instead, the aim is on how and on what grounds ABA can define certain behaviour as good/bad, healthy/unhealthy and from there define desired outcomes. As ABA is concerned with humans in a social reality, this paper argues that it cannot detach itself from norms and values. Drawing on the works of the Norwegian educational philosopher Hans Skjervheim, this presentation and the paper it builds upon will critically discuss ABA's proclaimed position of objectivity and neutrality. Arguing that neither a person's behaviour, the professional applying the method nor the defined outcome is in any way objective or neutral but always normative and socially conditioned. The ambition of this paper is therefore to illustrate some potential ethical issues that ABA risk to neglect. Issues such as the risk of the professionals imposing their own norms and values on the persons who are subjected to ABA.

The WHO European framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030: Issues, risks, and recommendations

Elena Rotarou¹, Dikaïos Sakellariou²

¹ *Universidad San Sebastián, Santiago, Chile*

² *Cardiff University, Cardiff, United Kingdom*

International evidence has shown that people with disabilities often experience worse access to health care services, which frequently leads to poorer health outcomes in comparison to the general population. Bearing this in mind, in September 2022 the 53 Member States of the WHO European Region adopted the Resolution of the “WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030”. The development of the Framework was led by Member States in the Region, in close collaboration with organisations of people with disabilities. The vision of the Framework is that, by 2030, people with disabilities will be fully included in health care planning, delivery, and leadership across the Region.

While the adoption of the Resolution is an important step towards the establishment of disability-inclusive health sectors, certain issues and risks could endanger the success of the Framework. Issues – that is, already existing problems – such as, the variability of Member States in terms of health care systems, infrastructure, and policy, and variability in terms of disability-related legislation addressing disability discrimination, can seriously impact on the Framework's progress. Risks – that is, future problems – include geopolitical instability, recession and/or stagflation, and ‘on paper’ adoption of disability-related measures, without real political commitment or actual change.

While certain risks cannot be avoided and many issues have complex solutions, it is important to anticipate such problems, and devise a plan or course of action to mitigate impacts, in close collaboration with organisations of people with disabilities. Undertaking a proactive approach based on the fruitful collaboration among Member States and

organisations of people with disabilities is key to the Framework's success and the protection of the rights and promotion of the health and wellbeing of people with disabilities in the European Region.

Leveraging critical disabilities studies to reimagine clinical letter writing for children with disabilities: A cascade of potential outcomes

Victoria Boyd,

University of Toronto, Toronto, Canada

Background:

Supporting children with disabilities at school requires collaboration between health professionals, parents, and educators within and across the health and school systems. As the primary mode of communication from clinics to schools, reports and letters can enable or hinder collaborative practice. In a previous study, our team leveraged critical disabilities studies knowledge to teach health professionals to write letters that challenge harmful biomedical conventions. In the current study, we explore the impacts of these letters, asking: how do parents and educators respond to letters informed by a critical disability perspective?

Methodology:

We conducted a qualitative exploratory study of the reactions and proposed actions of the recipients of clinical letters. Nine parents and eight educators (teachers, resource teachers, principals) participated in semi-structured interviews. Using letters written by health professionals as an elicitation tool, participants were asked to describe what they would do if they received the letter. Reflexive thematic analysis was used to generate patterns of meaning in the data.

Findings:

Letters informed by a critical disability perspective may spark a cascade of potential outcomes that can be conceptually grouped as humanistic, communication, collaboration, advocacy, and service delivery outcomes. Rehumanizing children and families by shifting how letters are written can facilitate dialogue, collaborative partnerships, and distributed advocacy. Collectively, these potential outcomes can enable effective delivery of school-based services and supports for disabled children.

Conclusions:

Our findings demonstrate that teaching critical disabilities studies to health professionals has the potential to address longstanding challenges at the clinic-school interface. In mapping the potential outcomes of letters informed by a critical disability perspective, this study establishes a link in the chain of impact between health professions education and health care practice. Our findings show that shifting how letters are written can improve the experiences of parents and educators of disabled children.

12-05-2023

13:40 - 15:00 - **Deafness II with International Sign Language - Sign language and policy** Grand Hotel - Háteigur /

Sign language education and language policy

Kim Kanstrup Kjeldsen,

CFD, Copenhagen , Denmark

CFD, formerly "Center for the Deaf", is the largest supplier in Denmark of services for the deaf, people with hearing loss or deafblindness as well as deaf people with additional disabilities.

For at least 30 years, CFD has built up and developed its own sign language education where the organization's employees are taught Danish sign language. The aim is for the deaf and hearing employees to be able to communicate with each other and with their deaf and deaf-blind clients.

Although many employees take a sign language course, it turns out that not everyone reach a sufficiently high level. It can affect the well-being of clients and the working environment for employees.

Some of the measures the company has taken, and in which I am participated, include:

Sign language training:

The education has gone through a quality boost of content, form and method as well as professional qualifications. In 2022, the program was recognized by the Accreditation Institution.

In order for this recognition to help raise the level of sign language among employees at CFD, I am part of a project to continue and ensure the high quality of the teaching. Example by implementing a CEFR-System, and having clear learning objectives drawn up. In addition, a didactic basis must be developed, as well as more and improved learning guides for the individual lessons.

Language policy:

This has existed since 2014 and is continuously revised. No later than 2022, as a new initiative, CFD had some action instructions drawn up that concretely describe what responsibilities managers and employees have and how they can be executed. An important element in the action instructions is that local departments can apply for a sign language consultant to discuss improvements and development in the individual department.

On both sides of the seminar room - inclusive university for all

Silvia Kopp-Sixt, Anna Steiner, Barbara Levc

University College of Teacher Education Styria, Graz, Austria

Till 2013, special education teachers in Austria needed to have general pedagogical competences to teach children of all grades. In addition, people with disabilities were mostly excluded from teacher education programs already failing at the admission procedure. In 2013, the Law regarding the Austrian's teaching profession changed. Becoming a teacher is an age-related decision (primary/secondary age level), not the decision for a special school type anymore. Inclusive education represents an obligatory basis for all teachers on a general level and an optional focus leading to specialization (Feuser & Maschke, 2013; Häcker & Walm, 2015; European Agency, 2015). What is also completely new and a "first time for Austria" is the possibility for students with disability to gain admission for teacher education studies on bachelors and masters level starting since 2015/16.

Professors, lecturers, researchers, members of the administrative board as well as study applicants and students enrolled in teacher training represent nowadays an inclusive cell in an emerging inclusive society. The number of teacher students with special needs in the city of Graz, Styria, educational cluster south-east of Austria, is growing (2022/23 $n \approx 15$, not considering the group of successful graduates since 2015). At first, the data basis comprises a qualitative content analysis of personal "audio biographies" (perspective 1) as a result of written guideline interviews ($n \approx 350$) from students without and with hearing impairment or deafness enrolled in teacher education. After that, the presentation of practical cases (perspective 2) invites to share experiences and discuss possibilities and the conditions of success for inclusive university development taking into account the essential multiperspectivity and flexibility in communication and interaction. In addition, universities represent inclusive places of employment for professors, researchers and administrative personnel with special needs. Core findings of focus groups with colleagues with special needs (perspective 3) are presented.

Deaf identity under pressure: experiences of Deaf persons in Iceland

Kristinn Diego, Stefan Hardonk

University of Iceland, Reykjavík, Iceland

The context in which Deaf individuals develop and maintain their identities and communities has undergone dramatic change not least with the widespread use of cochlear implants. This is also very much the case in Iceland, where the Deaf community faces challenges that threaten its very existence. This empirical study explored how culturally deaf (Deaf) individuals experience developing and maintaining a positive identity within different domains of life, which includes family life, working life, and social life. This issue was studied against the background of different scholarly approaches to what constitutes deaf identities and how they are shaped. The study places emphasis on deaf identities as multifaceted and dynamic, and it explores identity construction within the context of social interactions. Semi-structured interviews with individuals who identify as being part of the Icelandic Deaf community were transcribed verbatim and analysed employing a phenomenological perspective. The results indicate that a shortage of diverse and meaningful social interactions within the Deaf community constitutes an important barrier in developing and maintaining a Deaf identity. Participants reacted in different ways, with some individuals exploring opportunities outside of the Deaf community of Iceland, however this did not always lead to more opportunities for Deaf identity construction. While participants place much importance on Deaf identity and community, the analysis sheds light on how being Deaf in Iceland constitutes an insecure identity with many obstacles in its way. These findings from Iceland underline the importance of addressing in policy and practice the challenges

Deaf individuals are facing in order to reverse the insecurity of Deaf identity and community in many parts of the world.

Sign language interpreting - a quick fix for inclusion?

Hilde Haualand¹, Maartje De Meulder²

¹ *OsloMet, OSLO, Norway*

² *Hogeschool Utrecht, Utrecht, Netherlands*

This presentation rethinks the impact of sign language interpreting services (SLIS) as a social institution. Although both deaf people, sign language interpreters and service providers experience considerable limits in communication even with an interpreter present, SLIS have become tied with ideologies of 'access' and 'inclusion' for deaf people (De Meulder & Haualand 2021). Notwithstanding the legal recognition of sign languages in an increasing number of countries, governmental language policies still often confine the right to sign languages as a right to SLIS, not as a right to access to language-concordant public services.

The often uncritically proposed and largely accepted solution at the institutional level to lack of access for deaf people, seems to be increasing the number of interpreters. Using documented examples from education and health care settings, we raise concerns that arise when SLIS become a prerequisite for public service provision. Since the outbreak of Covid-19, there has also been a rapid increase in the presence of sign language interpreters at public briefings, but few governments have made an effort to provide public information in sign language outside these interpreted briefings. In the presentation, we will discuss if or how the current ideologies surrounding SLIS contributes to replacing or concealing the need for language-concordant education and public services, and if the right to sign language is confined to interpretations of spoken language provided by mostly hearing second language users of sign language. This presentation is also a call for a more critical analysis and more scrutiny about how different kinds of "accesses" can be implemented without SLIS, and more awareness of the contextual languaging choices deaf people make beyond the use of interpreters.

De Meulder, M., & Haualand, H. (2021). Sign language interpreting services: A quick fix for inclusion? *Translation and Interpreting Studies*.

12-05-2023

13:40 - 15:00 - **Culture and history II - Medieval Disability Studies: Challenges and Commonalities** ÖBÍ 2 - Sigtún 42 /

- Moderator: Yoav Tirosh, Háskóli Íslands

Disability in Fifteenth Century Iceland

Yoav Tirosh,

Háskóli Íslands, Reykjavík, Iceland

Investigations into disability and other embodied difference in medieval Iceland are a relatively new avenue of research, only taking full swing in the last decade and a half. Hitherto, the focus of these studies has mainly been on various corpuses of the Icelandic sagas (such as the sagas of Icelanders, kings' sagas, and contemporary sagas), myth, or legal codes, though of course there are exceptions to this rule. The sagas, written between the late twelfth to fifteenth century are usually examined in light of the grand Icelandic narrative of civil war and subsequent takeover of the commonwealth by the Norwegian King during the thirteenth century. As a consequence, historical and literary history research of Iceland have tended to focus on the thirteenth century, with the fourteenth century relatively neglected and the fifteenth century treated as an afterthought. Disability Studies in Old Norse, due to this lack of available and relevant research, tended to follow suit.

This paper sets the stage for a more thorough examination of the Icelandic fifteenth century in the context of medieval disability. Since saga dating is complex and hard to rely on, the research instead focuses on legal material as well as the wide supply of diplomatic material left to us by texts such as church inventories, letters, land deals and testaments. The two main questions posed are 1) where can we find the manifestations and representations of disability in these sources?; and 2) what do the legal and societal conditions of disabled people reveal to us about attitudes towards embodied difference at the end of the middle ages? Connections with contemporary developments in Denmark, Germany, England and Norway—all exerting their financial, political and cultural influence on Iceland in various levels during that period—will be briefly outlined.

Mythopoeic Scars: The Life and Afterlife of Injury

John P. Sexton,

Bridgewater State University, Bridgewater, MA, United States

The persistence of injury as a feature of saga-age writing is widely attested. The lived experience of life-changing damage resulting from violence made for a highly adaptable and recognizable feature of the semi-historical writing of the period. This ubiquity made injury a trope, one which could be deployed by authors for narrative, didactic, or even historicist purposes. Reflections on injury are almost commonplace in saga writing, from the grim humor of dying men commenting on their injuries to poets reflecting on their losses to the strange links between the dreaming and waking worlds. And of course, what could be

reflected upon after the fact could be anticipated, either through exposition or foresight. Injuries thus reverberate through and across narrative structures. The resulting “echoes” carried mythopoeic weight and invite narrative accounting.

Considered in this light, reflections on injuries in dreams, verses, and reported speech could be conducted in imitation of Eddaic myth, where the gods provided exempla for mutilated bodies possessed of mythopoeic significance. Like the theophoric names common in medieval Scandinavia, injuries linked the experiences of gods and men. The models of maimed gods provided not only the plausible claim of certain injuries as *imago dei*, but encouraged more generally the inscribing of injury with meaning. But such reflections also participated in a more prosaic renegotiation of the impaired figure’s body and self-knowledge. An established person, distorted due to injury, required re-imagining in a way the unmarked body did not. The resulting matrix of meaning allowed each injury to speak for itself, or at least to be spoken for. This paper will consider the mythopoeic significance of several injured or distressed bodies in saga literature, centering on the stories of Án hrísmagi of *Laxdæla saga*, Gestr Bárðarson of *Barðar saga snæfellsáss*, and the eponymous Þórsteinn uxafótr of *Þórsteins þáttur uxafóts*.

„Á englum Krists og andskotans, eins og munur á fljóðum“: Guðmundur Bergþórsson’s relationships with women in his own words and in later folk legends

Alice Bower,

Háskóli Íslands, Reykjavík, Iceland

Guðmundur Bergþórsson (1657-1705) was one of Iceland’s most prolific poets of *rímur* (e. metrical romances). His works are preserved in over 400 manuscripts, with some poems being orally transmitted in rural Icelandic households up until the 20th century. Guðmundur’s works are not only of interest for scholars of post-medieval literature and indeed folk music tradition, but in parts they also provide valuable insights into the experiences of a physically disabled man in rural 17th century Western Iceland. In some of Guðmundur’s *rímur* and poetry, we see how descriptions of life with disability are conveyed in a way that makes use of stylistic conventions specific to the genres in which Guðmundur composed. He addresses how he became disabled at around four years of age, the vulnerability he experienced through his youth, his appreciation of help received by friends and family and the restrictions on his ability to do physical labour.

In 19th century folkloric manuscripts, a different picture of Guðmundur emerges. In these narratives, his disability features much more prominently and descriptions are marred by notions of disability as personal tragedy. Associations with the supernatural are strong. Guðmundur’s mother Þorbjörg Guðmundsdóttir is characterised as a practitioner of black magic, bearing direct or indirect responsibility for his disability. 19th century folklore collectors express the view that this early incident shaped Guðmundur’s view of women, supporting this argument with poetry attributed to him. This paper seeks to compare the picture painted by the early folklore collectors Gísli Konráðsson and Bólu-Hjálmar with Guðmundur’s own representation of his relationships with women throughout his life- in particular, in his poems “Vinapökk” and “Skautaljóð”. Through this approach, I aim to scrutinise the development and transmission of legends linking disability with the supernatural and maternal culpability. Finally, I address the impact of the working methods of later folklorists.

Sacrifice, Disability, and Body Metaphors in William Blake's *The Book of Ahania* (1795)

Sharon Choe,

University of York, York, United Kingdom

The body politic figures society within a metaphorical body to imply that diverse parts of society are united within the parameters of the nation. These metaphors are typically predicated on wholeness—in other words, an able-body politic—but in the poetry and art of William Blake (1757-1827), this model is disassembled to reveal a nation body that grapples with the meaning of embodiment.

Eighteenth-century Northern antiquarianism—a literary and artistic movement interested in the North and Norse culture—was used to survey Britain's collective anxiety over its identity during the eighteenth century. Scholars, poets, and artists across the British Isles presented a mediated ancient Scandinavia; they recast it as a land of wild, untamed liberty from which different British heritages could source cultural narratives.

In *The Book of Ahania*, the figure Fuzon is deformed and killed by his father Urizen before being sacrificed in a pseudo-Crucifixion scene. While the Christian iconography is obvious, I argue that a closer textual reading reveals that this scene also has roots in eighteenth-century Northern antiquarianism. It is also part of Blake's broader examination of a British body politic. As such, I suggest that the death and deformity of Fuzon, as well as the disfigurement and disabling of Urizen prior to Fuzon's death, contests Christian visions of renewal and restoration of an able body.

This paper will consider the importance of disability and deformity when examining the body politic, specifically in relation to eighteenth-century Northern antiquarianism. It will argue that the framework of Disability Studies can offer alternate ways of reading body politics, allowing for a more nuanced reading of body metaphors during this period.

12-05-2023

15:15 - 16:35 - **Childhood disability II - Rehabilitation** Hilton Nordica meeting room D /

Rehabilitation, Blindness and self-identity Exploring the ideological assumptions embedded in rehabilitation practice

Michelle Botha,

Stellenbosch University, Cape town, South Africa

Transitioning into life with visual impairment (VI) involves not only navigating changing visual ability but negotiating a new social and personal reality. This transition is likely to be experienced as a traumatic assault on both self and belonging, particularly given negative cultural beliefs about blindness prevalent in society. In this precarious subjective position, newly blind persons may be vulnerable to internalising powerful messages about their new place in society, as well as the social behaviours they are now expected to adopt.

Rehabilitation plays a key role in this regard, as the referral point for most individuals once VI has been diagnosed. Therefore, it is important to carefully consider the assumptions about blindness that are explicitly and implicitly communicated through rehabilitation practice.

This paper presents findings from qualitative research which explored the ideological assumptions embedded in VI rehabilitation practice in South Africa. A Foucauldian discourse analytic approach was used to analyse in-depth interviews with rehabilitation service providers and users, bringing to light the meanings about blindness, capability and social acceptability that circulate in rehabilitation. The research suggests that these meanings establish firm imperatives towards a culture of not only practical, but also emotional coping, which may disallow healthy emotions concerning loss and struggle, and limit newly blind persons in the development of authentic self-identities.

This work sheds light on a broader societal investment in promoting particular, acceptable ways of being for persons with VI, and persons with disabilities in general. It suggests that newly blind persons are drawn into an imperative to manage and limit disability difference as a means to gain inclusion into an inaccessible and unequal world, often with psycho-emotional costs.

Find your track – a study transition phases for youth with disability

Ellen Hæhre,

Beitostølen Helsesportsenter, Beitostølen, Norway

Introduction

Beitostoelen Healthsports Centre (BHC) is a rehabilitation centre, providing group-based re/habilitation services for children, youth and adults with disabilities. Adapted physical activity combined with resource focused medical and pedagogical follow-up, are guiding the program. The purpose of this study was to strengthen the transfer from the rehabilitation stay to the home environment, aiming to optimise activity and participation adapted to the total life situation, and thereby supporting the transition phase from youth to adulthood.

Method

The four week rehabilitation program is led by a multi-professional team. Individual goals and peer learning are emphasised. Strategies to strengthen the transfer process were; Interaction with local service providers, digital follow-up, thus developing tailored models for follow-up over time.

Two focus-group interviews were conducted, with nine and eight participants, respectively, 17-28 years. The theme discussed was transition phases, experiences, and advice to others. The interviews were recorded, transcribed, and analysed according to qualitative thematic analysis.

Results

The transition phase for youth with disabilities was challenging in most municipalities, with undesirable variation in services. The need for early preparation was a main concern, regarding both individual transition and service transition. The division of responsibility across services in the transitional phases was unclear. Lack of information transfer and late planning were common challenges. Extensive competence in the service systems was fragmented and lacked systematisation.

All the participants had digital follow-up with Flowzone after the rehabilitation stay according to an agreed plan established with local professionals before the end of the stay at BHC. The youth and their parents felt safer during the transition phase through increased preparation, empowerment, and competence

Conclusion

The use of digital follow-up with Flowzone provided simple, secure, and fast contact with the participants, and thus worked as a support during the individual and service transition in the local community.

Parents' experiences of a family-centred rehabilitation stay for their children with disability

Elisabeth Helle,

Beitostølen helsesportsenter, 2953 Beitostølen, Norway

Background: Children with physical disabilities are less physically active than their peers without physical disabilities. An important factor to increase their participation, is a family-centred focus. The purpose of this study was to examine how the parents of children with diverse disabilities experience rehabilitation stays at Beitostølen Healthsports Centre. This could provide insight in how to strengthen the parents' role during the rehabilitation stay to ensure adequate transfer of activities and participation to the local environment.

Material and method: Qualitative study with semi-structured interviews with six parents who had participated in a rehabilitation stay. Each interview lasted for approximately sixty minutes and was recorded, transcribed and analysed with systematic text condensation. Bronfenbrenner's developmental ecological model, as well as a family centred approach and empowerment were used as theoretical frameworks.

Results: The parents described that they gained competence, skills, awareness and feeling of safety after a rehabilitation stay. However, the follow-up also demanded great effort, time and adaptation on their side, to transfer some elements to the local environment. Challenges around acceptance and understanding also came up. Parents described sharing experiences with other parents, training activity skills, using activity aids, competent supervision, and seeing the resources and possibilities instead of the limitations as key factors for motivation and testing of new activities. They also emphasised the experience of mastery, which strengthened their belief in both their own and the children's competence.

Conclusion: This study showed that parents' experiences in a rehabilitation stay played a major role for their children's participation in leisure activities and social contexts at home. These findings may be linked to experiences of empowerment and competence in connection with transferring activities to the local environment.

Key words: parents experiences, rehabilitation stay, transfer of competence, children with disability, family-centred

Time processing and daily time management in children and youth age 10 – 15 years old with and without autism

Gunnel Janeslätt¹, Birgitta Wennberg², Annika Sköld³,

¹ *Center for Clinical Research Dalarna, Uppsala University, Falun, Sweden*

² *Center for Social and Affective Neuroscience, Linköping, Sweden*

³ *Karolinska Institutet, Stockholm, Sweden*

Abstract

Introduction: Children with disabilities have an increased risk of lagging behind their peers in the development of time processing and time management in everyday life, which can have major consequences on schoolwork, home life and leisure time. Children with autism have difficulties in daily activities related to time i.e starting and finalizing activities and switching from one activity to another. Time assistive devices and training can compensate for these difficulties, but for that, knowledge about the children's time processing and the daily time management are needed. Children with disabilities like Spina bifida have a lower level of time processing and daily time management than typically developing peers.

Corresponding knowledge for children with autism is lacking.

Objectives: The aim of the research project was to compare time processing and daily time management in children with and without autism aged 10 - 15 years.

Method: This is a descriptive and comparative cross-sectional study, based on a convenience sample. The target group is children with autism (n= 197) and typically developing children (n=809) aged 10-15. Data was collected with an objective instrument Kit for Assessment of Time processing ability (KaTid-Youth ver 19). Daily time management was rated by the parents using Time-PS 10 – 17 years. Analyzes were made with descriptive statistics, average values with standard deviation/year in age and comparative statistics.

Results: Preliminary results show a significant difference in time processing and in daily time management between children with autism and typically developing children aged 10 – 15 years.

Conclusion/Practical application: The results provide increased knowledge about time processing and parent-estimated daily time management in children with and without autism. The knowledge can provide guidance for professionals to provide adequate support to children with autism for increased daily time management, possibly leading to increased independence and participation in their everyday life.

12-05-2023

15:15 - 16:35 - **Education, inclusion and the body** ÖBÍ 1 Sigtún 42 /

Dys/appearing Bodies in the Secondary School Classroom: Young People with Dwarfism Dys/Appearing as 'Out of Time' and 'Out of Place'

Antonios Ktenidis,

University of Sheffield, Sheffield, United Kingdom

"Once we start talking in the classroom about the body and about how we live in our bodies, we're automatically challenging the way power has orchestrated itself in that particular institutionalized space" (hooks, 1994: 136-137).

Schools treat students' bodies as an 'absent presence', that is, bodies are expected to fade in the background, as they are deemed disruptive to learning. Nevertheless, not all bodies have the 'ability' to disappear, with some bodies appearing as 'excessive', including the disabled body. This paper explores how the bodies of young people with dwarfism dys-appeared (Leder, 1990) or appeared as a 'problem' in the secondary school classroom in the United Kingdom. Drawing on the stories of 20 young people (between the ages of eleven and thirty years old), which are analysed through the lens of phenomenological disability studies, this paper presents stories of dys-appearance as 'out of place' and 'out of time', looking into how the young people's bodies (were made to) appear as 'out of time' and 'out of place'. These stories highlight how young people with dwarfism navigate dis/ableist school timeframes and spaces, as well as how they disrupt them, through the introduction of crip (school) time, for instance. The repercussions of dys-appearance and the attempts to discipline such 'unruly' bodies are also considered. Finally, the disruptive potential of disability to reconsider schooling's conventions is brought up.

Reference List:

hooks, b. (1994). *Teaching to transgress: Education as the practice of freedom*. New York/London: Routledge.

Leder, D. (1990) *The Absent Body*. Chicago, IL: University of Chicago Press.

Including children with special needs in Physical Education at a public school in Denmark by using Co-teaching: A Qualitative Design Based Research

Anette Bentholt¹, Lonni Nielsen²

¹ *University College North, UCN, Skørping, Denmark*

² *University College North, UCN, Hjørring, Denmark*

The number of children with special needs as autism, ADHD and anxiety are increasing in Denmark. These children are less physical active in their daily life, and they have a poorer mental health. About 9% of the children in the Danish public schools have special needs and 1/3 of these children do not like to go to school, and/or exempt from a subject, which most often is Physical Education (PE) (DH, 2020). PE Teachers also find it difficult to teach children with special needs (Zeelen et al., 2018). Co-teaching (CT) is a systematic pedagogical collaborative approach (Friend, 2017), which have shown good results for including children with special needs in academic settings, but CT has not yet been tested in PE.

The overall research question is: *Can co-teaching as a teaching approach create better opportunities including children with special needs in PE?*

The empirical research took place in one public school in Denmark, 2021. Two PE teams participated consisting of two-three teachers and classes in each. Our research is based on Design Based Research (Armstrong et al, 2020). Four focus group interviews with the PE teams before and after the research period, 10 participant observations of PE lessons on each team, and 10 individual semi-structured interviews with pupils with special needs. The

empirical framework was analyzed by use of micro-sociologist Erving Goffman's theory about *Stigma* (2009) and *Role Play* (2014).

Findings shows that systematic use of CT can include more children with special needs in PE. Especially small groups and a consistent sharing of the teacher role in PE has a positive influence. The PE teacher's attention to team formation is very important, otherwise it can make exclusion. CT can also create resistance to change among the teachers if they experience to little preparation time or loss of self-control.

Dealing with disability as "matter out of place": Emotional issues in the education of learners with visual impairment

Brian Watermeyer,

Stellenbosch University, Cape Town, South Africa

Globally, education of children with disabilities increasingly occurs in inclusive school settings, requiring specialised teacher education. Scholars emphasise both relational and instrumental skills, to overcome prejudice and exclusion. Visual impairment (VI) is emotionally evocative, presenting particular challenges to inclusion. Using data from in-service teacher training for VI inclusion in South Africa, this theoretical paper explores the personal and emotional barriers which teachers must negotiate surrounding the 'new reality' of VI in their classrooms if successful inclusion is to be achieved, and how teacher education may support this. We set qualitative data from an in-service short course for teachers of VI learners against ideas from disability studies, critical psychoanalysis and anthropology, conceptualising relational issues arising from VI in the classroom. Due to VI's evocation of unconscious anxieties in the observer, we argue that the experiences and needs of children with VI may be felt as 'matter out of place' in the classroom, confounding inclusion. Teacher anxiety threatens the capacity for emotional containment and creativity, undermining the secure relationship which is elemental to successful learning. To manage the experiences, feelings and needs of VI learners, teachers require education which facilitates processing of their own emotions surrounding this evocative form of disability.

Keywords: Visual impairment, inclusive education, relational competence, unconscious, psychoanalysis, teacher education

Uses of Braille in Different Faith Traditions

Brian Bennett,

Niagara University, Lewiston, NY, United States

This paper discusses some uses of braille in different faith traditions. Starting with Louis Braille (1809-1852), who was a devout Catholic and accomplished church organist, religious adherents have adopted and adapted the six-dot writing system for their own purposes. Despite the increasing prevalence of digital technologies, the tactile code remains an invaluable resource for religious practitioners. This paper offers a kind of phenomenology of braille in contemporary practice, with examples from the scriptural, ritual, and material dimensions of different faith communities around the world.

In the nineteenth century, religious texts were some of the first to be printed in braille, as well as in rival systems like Moon type. Today, brailled versions of the Bible, Qur'an, Bhagavad Gita, and other canonical texts are readily available. Braille prayerbooks allow individuals to participate more fully in their community's rituals, such as the Catholic Mass or Jewish Seder. Moreover, the writing system enables individuals to pursue their vocation as priest or rabbi. Drawing on interviews, the paper enumerates some of the complexities of those career paths. Finally, braille can augment the artistic and material aspects of religion -- for example, with inscriptions on touchable Russian Orthodox icons.

The paper concludes with some recommendations for future research on this important but neglected topic.

Alekseeva, E. (2019) "Molitva na konchikakh pal'tsev." *Tserkovnyi vestnik*. http://www.e-vestnik.ru/analytics/molitva_na_konchikah_10449/

Mellor, C. M. (2006) *Louis Braille: A Touch of Genius*. National Braille Press.

Suit, N. (2021) *Qur'anic Matters: Material Mediations and Religious Practice in Egypt*. Bloomsbury Academic.

Tobe, C. B. (2008) *History in the Making: The Story of the American Printing House for the Blind, 1858-2008*. Butler Books.

Weygand, Z. (2009) *The Blind in French Society from the Middle Ages to the Century of Louis Braille*. Stanford University Press.

12-05-2023

15:15 - 16:35 - **Criminology - Criminology and disability** Hilton Nordica - Meeting Room G /

Disability, home takeovers (cuckooing) and criminal exploitation

Stephen Macdonald¹, CATHERINE DONOVAN¹, John Clayton²,

¹ *Durham University, Durham, United Kingdom*

² *Northumbria University, Newcastle upon Tyne, United Kingdom*

This paper examines the practice of how home takeovers, i.e., cuckooing, occur and how disabled people are at particular risk of this form of criminality. Cuckooing is often referred to as a recent phenomenon that has emerged due to changes in organised crime business models, particularly in the illegal heroin or crack cocaine drug markets. Traditionally, individual perpetrators and organised criminal groups (OCGs) have engaged in criminal activity within a fixed geographical location. However, improvements in policing techniques that can pinpoint individual perpetrators' and/or OCGs' locations based on the distribution of criminal activities have resulted in a significant disruption to the illegal drug trade. In response, OCGs, using new digital and mobile technologies, have begun to change their business model in the UK. This business model expands their geographical reach across regions and counties within the UK, and this is referred to as county lines. This study employs a qualitative biographical methodology that collects data from disabled people who have been victimised this way and practitioners who have worked with them. Although

research in the field of cuckooing is dominated by links between county lines OCGs and home takeovers, this paper suggests that the phenomenon of cuckooing is far more mundane and localised than previously considered. The findings illustrate that social isolation, loneliness and a lack of community services can create a space where the exploitation of disabled people can flourish. We conclude by demonstrating that cuckooing predominantly occurs at a local level, perpetrated by local people, rather than by county lines organised criminal groups. In fact, we suggest that local cuckooing often predates county lines home takeovers.

Disability, Intersectionality and Sexual Violence: Barriers within the policing of sexual violence and lessons for future practice

Leah Burch¹, Andrea Hollomotz²

¹ *Liverpool Hope University, Liverpool, United Kingdom*

² *University of Leeds, Leeds, United Kingdom*

Disabled people are more likely to experience sexual violence than their non-disabled counterparts. However, disabled people's access to the criminal justice system can impede their opportunity for justice. Drawing upon findings from a Ministry of Justice funded research project that was conducted in England and Wales, this paper explores the barriers that disabled people might experience when reporting their experiences of sexual violence to the police. These barriers are both attitudinal and practical which can mean that disabled people are not afforded an equal opportunity to access a rights-based, social justice response. More specifically, I pay attention to the ways in which disabled people's intersectional identities and histories are ignored or avoided by the criminal justice system. Importantly, I draw upon these barriers as an opportunity to present a series of solutions and recommendations. While these barriers and recommendations reflect the lived experiences of disabled victim-survivors of sexual violence within the context of England and Wales' criminal justice system, they can be adapted and implemented in a variety of settings.

"I just felt that I was just somebody who was there to be abused": Disabled rape victim-survivors talk about their journeys towards realisation

Andrea Hollomotz¹, Leah Burch²

¹ *University of Leeds, Leeds, United Kingdom*

² *Liverpool Hope University, Liverpool, United Kingdom*

This presentation reports on a Ministry of Justice funded qualitative research project with 39 disabled rape victim-survivors from England and Wales. It draws on findings from 30 interviews and two focus groups, which used creative methods to enable disabled victim-survivors to map out their journeys towards accessing victim support. Yet, before they could embark on their help seeking journeys, many respondents experienced delayed realisation. Some needed support in coming to the understanding that their sexual boundaries had been crossed. This presentation highlights the importance of understanding delayed realisation in terms of broader social contexts.

A significant proportion of the sample had been targeted with repeat incidents of different types of interpersonal violence, including hate crime, sexual and physical violence, emotional abuse and abusive care practices. As the quote in the presentation title indicates,

this led to some experiencing intrusive behaviours as mundane occurrences. Those experiencing sexual violence by a spouse were caught up in a complex web of coercive control and confusing emotions that hindered realisation. Realisation was further compromised by being ignored, misunderstood or disbelieved when seeking to tell a trusted person, as well as by hurtful and disablist responses when individuals attempted to reach out to support services and the criminal justice system. Those who reported multiple and repeat incidents of violence were least likely to access support and justice.

This presentation concludes that a broader understanding of social causes that work to normalise the continuation of violence towards disabled people is required. This starts with challenging mundane intrusions and disablism, through to making victim support services inclusive to disabled service user and ensuring that those working with disabled people are equipped to listen in a way that can facilitate realisation.

Abolition and Disability Politics

Liat Ben-Moshe,

University of Illinois-Chicago, CHICAGO, United States

The framework of abolition (prison, penal, police, State) have gained significant currency in the past few years, across North America and internationally. This presentation aims to explain this framework (especially in the North American context) and show the usefulness of this approach, as well as its intersection, with disability politics. I will draw on data from my book (*Decarcerating Disability: Deinstitutionalization and Prison Abolition*, University of Minnesota Press, 2020) but will elaborate on current connections, which became more prominent after and during 2020. For example- the proliferation of mental health jails and units, drug and mental health courts and other examples show the need to deeply understand the connection between disability liberation, racial justice and abolition.

The circulation of the concept and praxis of abolition is a consequence of organizing and theorizing on the ground from the perspective of those most susceptible to state violence (including police brutality), mainly people of color, indigenous, women and gender non confirming people etc. and their intersections. I will introduce and discuss the framework of Crip/Mad of Color Critique as a way of building on these knowledges and connecting them to disability justice and to disabled and mad people. I will discuss how this perspective connects to abolition, and how it connects but also significantly differs from human rights and disability rights frameworks.

(to organizers- if interested in me doing this as a workshop and not a paper, please contact me).

Perceptions and experiences of women with disabilities on intimate partner violence

Cartrine Anyango, Isabel Goicolea, Fredinah Namatovu

Umeå University, Umeå, Sweden

Background: Intimate Partner Violence (IPV) is one of the major threats to the health of women with disabilities. Current research suggests that women with disabilities have nearly double the lifetime risk of intimate partner violence and they experience higher rates of all

kinds of violence than men with disabilities and non-disabled men and women. This is due to disability-related factors comprising dependency on others for support, difficulties in being believed, and social and physical isolation. Research exists on IPV against women in general but very few on women with disabilities. This study aimed to explore the perceptions and experiences of women with disabilities on intimate partner violence.

Methods: Qualitative study using in-depth interviews with eleven women with disabilities, aged 18 years onwards. We used reflexive thematic analysis with a constructivism epistemological standpoint.

Results: We developed four themes. Theme one; violence everywhere; illustrated by exposure to several forms of violence, from multiple abusers over one's life course. Theme two; violence that needs to be proved; women were faced with a heavy burden to prove their legitimacy as victims of psychological abuse. Theme three; violence does not end by leaving the abusive partner; it continued beyond separation/divorce due to co-parenting and the women's financial instability. Theme four; stepping up and taking 'control'; participants were able to exit abusive relationships and gained control of their lives because of; support from family and friends, having had enough, for the sake of children and having shared experiences with other abused women.

Conclusion: Women with disabilities experience intimate partner violence in all its forms. The support systems should take into consideration the needs that women with disabilities subjected to violence may have while in an abusive relationship and even after leaving it, but even more importantly service providers' capacity should be strengthened to detect and handle all forms of IPV, especially psychological abuse.

12-05-2023

15:15 - 16:35 - **Deafness II with International Sign Language - Languages and learning**
Grand Hotel - Háteigur /

Learning Multiple Languages: Challenges for Students with Deafness in secondary school in West Bengal, India

Sneha Dasgupta,

Tata Institute of Social Sciences, Mumbai, Mumbai, India

Multilingualism is more visible at the individual level as it basically refers to the ability to use more than one language. In West Bengal, D/deaf students face intense barriers to learning language because of inaccessible environments. India has 22 official languages so, as a multi-linguistic country, in West Bengal Board of Secondary Education, each student has to learn three languages for three years which are Bengali as the first language, English as the second language and Hindi or Sanskrit as the third language.

Deaf children born into hearing families often feel excluded from family conversations and activities. This gap increases over time if detection of deafness does not happen at an early stage and early intervention does not take place. With respect to education, Marschark (2013) said that a teacher cannot teach deaf students like they are hearing children who cannot hear. It is not about ears, speech or sign language. It is about finding deaf students' needs and strengths. In India, if and when deaf students attend school, it is also compulsory

for them to learn languages. While in mainstream schools, students with deafness have to learn three languages, whereas special schools provide the option of learning two languages often related to the consequences of social and academic exclusion.

The objective of this qualitative and explorative study is to understand the difficulties and challenges of multiple and additional languages for students with deafness. In West Bengal, in-depth interviews with signers and speakers in Deaf and Mainstream education have been conducted and their academic life experiences are the focus of the analysis.

Learning English as a foreign language through the eyes of Deaf students

Katharina Urbann¹, Alina Gervers¹, Melanie Kellner², Kristin Gross³

¹ *Humboldt-University of Berlin, Berlin, Germany*

² *Vocational College for the Deaf and hard-of-hearing Essen, Essen, Germany*

³ *University of Cologne, Cologne, Germany*

Teaching English as a foreign language to Deaf students has been broadly discussed as a major challenge for teachers, as for example a specific training on how to teach English to Deaf students is almost nonexistent. Inadequate teacher education leads to frustration and a wide spectrum of classroom practices, i.e. some teachers merely use written English, others mix signs from the national Sign Language (i.e. German Sign Language (DGS)) and combine them with English mouthing, others introduce signs from an additional sign language, mostly American Sign Language (ASL; Kontra, Csizér & Piniel 2015; Urbann 2020). Even though the experiences of Deaf students themselves may reveal important implications for teaching English to Deaf students successfully and future teacher training, the perspective of Deaf students themselves has not been researched yet. According to this desideratum, the goal of this research project is to ascertain the experiences of Deaf students who learnt English at German schools for the Deaf. To reach this goal semi-structured interviews with former Deaf students were conducted (n=12) and evaluated with Mayring's qualitative content analysis (Mayring & Fenzl 2019). The results show that (1) the exclusive use of written English demotivates the students; (2) the combination of DGS and spoken English confuses and demotivates the students; (3) using ASL in the English as a foreign language classroom meets the communicative needs of the Deaf students, motivates the students to learn English and has a positive impact on the written English proficiency of the Deaf students.

SignNets: multi-purpose digital semantic networks

Ineke Schuurman¹, Caro Brosens², Margot Janssens²

¹ *KU Leuven, Leuven, Belgium*

² *Vlaams GebarentaalCentrum (VGTC), Antwerp, Belgium*

Nowadays, digital language services should be available for all natural languages, but for most sign languages (SLs) this isn't the case. We are constructing a semantic network, a signnet (cf wordnets), starting with VGT (Flemish SignLanguage), but extendable to other SLs (part of SignON project (<https://signon-project.eu>)). While a wordnet consists of words, a signnet consists of signs. In signnets we collect hypernyms, hyponyms, homonyms, antonyms etc. of the signs. Links with wordnet are also provided, using the gloss included in

SL dictionaries. Such a gloss is in fact a label for a synset of signs, thus using a gloss to find entries results in finding synonyms, while in a wordnet using a word results in finding homonyms. However, synsets in SLs often deviate from those in the surrounding spoken language, they are often broader, sometimes more limited, or consist of more word classes. Sample sentences in both VGT and Dutch are included, together with pictographs (ARASAAC), descriptions of handshapes (plus position, movement, occupation, location) in picture-format, and larger sets of keywords (spoken language), HamNoSys or Sign_A notation. For SLs there is no generally accepted written form. Automatic sign recognition will also be possible (when available for the SL under consideration). Whereas existing SL dictionaries are our starting point, guaranteeing the quality of the signs, our signnet contains information to extend them (more keywords, plus homonyms, hyponyms etc, and pictographs). As not all end-users may want to see all of these, such additions should be showable at the request of individual users. The material included in SignNets could also be useful when developing tools to learn SLs or to improve existing knowledge, for example by using pictographs not only to explain the meaning of a sign, but also to find or learn a sign with a specific meaning.

12-05-2023

15:15 - 16:35 - Services II / Employment - Unpacking processes of work inclusion Grand Hotel - Huginn /

- Moderator: John Brauer, Örebro University

Social representations of gender and their influence in vocational rehabilitation

Ingrid Witte, Thomas Strandberg, Johanna Gustafsson

Örebro University, Örebro, Sweden

Although gender differences have been found in the outcomes of vocational rehabilitation and thus affecting the work inclusion process; little is known about the employment specialists' perceptions and experiences of working with men and women with disabilities.

Therefore, the purpose of this study was to explore employment specialists' social representations of gender in relation to work and vocational rehabilitation and how these social representations influence the employment specialists' work in the vocational rehabilitation process. A qualitative method of focus group discussions was employed. Ten focus groups were held with 40 employment specialists from four categories of vocational rehabilitation organizations in Sweden. Topic analysis was applied to the transcribed material from the focus groups.

Five themes with different social representations about gender and disability in relation to vocational rehabilitation and working life formed in the analysis: 1) differences in personal and health factors among vocational rehabilitation participants, 2) gender norms in society influencing vocational rehabilitation, 3) energy-intensive environmental issues influencing vocational rehabilitation, 4) gender-specific interactions in vocational rehabilitation, and 5) gendered paths in the welfare system. A conclusion that could be drawn from the study was that social representations of higher strains on women with disabilities compared to men with

disabilities both in private and working life is a possible explanation for gender differences in vocational rehabilitation and working life for persons with disabilities.

Can fidelity assessments enhance work inclusion of unemployed youth with less severe mental health problems?

Julia Salado-Rasmussen, Stella Mia Sieling-Monas

University College Copenhagen, Copenhagen, Denmark

Despite a growing body of literature, the use of fidelity assessments is still a rather novel approach in Danish active labour market programs. In this paper, we present insight from the Danish 'Reconnect project' implementing an intervention based on Individual Placement and Support (IPS) targeting unemployed youth with less severe mental health problems.

The project runs from 2019-2024 and rests on collaboration between researchers from University College Copenhagen and youth departments of three municipal job centres that implement the program following a detailed manual and training. In Project Reconnect critical components of the method are defined in a modified fidelity scale, aimed at measuring the level of implementation within three categories: staffing, organization, and services (Becker et al. 2015). Social workers within the project and their organizations are encouraged to implement the Reconnect method with the highest fidelity possible.

Based on repeated qualitative interviews with three supervisors and four middle managers and document analysis of fidelity assessments, we argue how fidelity assessments can enhance work inclusion by ensuring compliance with the method, managerial focus, and resources within organizational negotiations. Crucial elements in the day-to-day delivery of employment services if the good intentions of work inclusion are to become reality. We also address the implications of working with fidelity measures and discuss how this approach to evaluating frontline implementation also includes crucial limitations and dilemmas within a Danish welfare-to-work context. The presentation is based on existing research on the implementation of IPS (Bond and Becker, 2012; Frøyland, 2016; Bonfils *et al.*, 2017; Bonfils, 2019), evaluation theory (Vedung, 1997) and interview data from the Reconnect study.

"Active" and "passive" in labour market policies for people with disabilities

John Brauer,

Örebro University, Örebro, Sweden

Integrating people with disabilities in the work force has become a central policy goal in many welfare states. The goal conflicts with the ideology of care and passiveness that has characterised disability policy historically. This conflict can be seen against the development of active labour market policies, more generally, during the 21st century – a development characterised by reconfigurations between active measures and the access to financial support (often referred to as passive measures). Examples of such reconfigurations are activation and work-to-welfare, in a nutshell policy tools that condition access to financial support through participation in labour market programmes, which has been criticised for hollowing-out the embodiment of basic financial security.

The paper discusses the relation between active measures, aimed at including people with disabilities in the work force, and the access to financial support. It covers issues such as conditionality, unintended effects, and the work ethos, and how such issues play out (and do not play out) when active labour market policies are delivered for people with disabilities. The paper combines a conceptual discussion, based on a literature review, and interviews with people delivering labour market policies and/or administering financial support for people with disabilities. The paper adds to existing literature by critically examining potential pitfalls but also benefits of aiming at integrating people with disabilities in the work force. In terms of work inclusion processes, the paper discusses how access to financial support potentially shapes the involvement and experience of participants and staff – aspects that are likely to mediate to what extent the welfare state will be successful in work force inclusion of people with disabilities.

12-05-2023

**15:15 - 16:35 - Rehabilitation, technology and accessibility II -
Technology in the lives of disabled people** Grand Hotel - Setrið /

What do we do? What can we do?: Preliminary findings from research on digitally facilitating meaningful activities for adults with ID during the pandemic

Richard Gäddman Johansson,

Mälardalen University, Västerås, Sweden

This presentation aims to share and discuss preliminary results from an ongoing research project that investigates the digital leap triggered by the lockdown of daily activity centres for individuals with intellectual disabilities (ID) due to Covid-19. In Sweden, adults with ID who are not employed or enrolled as students have a right to support with meaningful activities, typically organized at or through daily activity centres. However, in the spring of 2020, many daily activity centres across Sweden closed overnight as a response to the escalating spread of Covid-19. The project analyses the digitalization process at five daily activity centres and its future development and relates to the important issue of digital inclusion for individuals with ID. Interviews have been carried out with staff members and overseers at the daily activity centres, individual service users, and support persons in the service users' home environments. Preliminary results reveal that staff members were left "fumbling in the dark" as they experimented with different ways of facilitating meaningful activities – both online and offline – with and for individual service users during a period when few knew what was possible, reasonable, or even legally permissible to do. As an added complication, the lockdown period revealed that access to computers, the Internet and software which would allow for visual and/or auditory engagements in the absence of immediate face-to-face interactions, was not something that all service users had. Additionally, access to the required hardware and software was sometimes not enough on its own, as other factors functioned as barriers that either hindered or made attempted meaningful activities utterly impossible to carry out, such as differing attitudes, competences, and available resources between the daily activity centre staff and support persons in the service users home environments.

Making customized information and communication technology (ICT) work for persons with disabilities living in residential settings

Anita Berg¹, Hide Guddingsmo¹, Gunn Eva Myren²

¹ *Nord University, Namsos, Norway*

² *Nord University, Namsos, Norway*

In contemporary society, being unable to take advantage of information and communication technology (ICT) create barriers to maintaining sustainable social relations. Not being able to operate ICT alone increases social exclusion and loneliness risk. Findings in prior studies have revealed that customized ICT can contribute to the maintenance and improvement of own social networks for persons with impairments. Thus, there is still a knowledge gap regarding adapting customized ICT in residential care. Based on interviews with residents, relatives and staff this study reports and discusses the benefits and concerns when adapting KOMP, an customized ICT product, for persons living in four different Norwegian residents. The analysis is conducted inspired by collective qualitative analysis. The findings underscore that adapting customized ICT/KOMP showcases the underlying tensions regarding self-determination, privacy and care when living, working and interacting with relatives in residential settings.

Online Experiences of Adults with Intellectual Disabilities: Personal Perspectives, and those of Carers and Professionals

Paraskevi Triantafyllopoulou, Jessie Newsome, Michelle McCarthy

University of Kent, Canterbury, United Kingdom

Background and Aims

The internet and social media are ubiquitous, and people with Intellectual Disabilities are increasingly going online. Despite the risks associated with being online, adults with Intellectual Disabilities can benefit immensely from internet access, and the myriad opportunities available. However, they face barriers to getting online, and to using the internet. The current study aimed to qualitatively explore the online experiences of adults with Intellectual Disabilities, and to also find out more about the perspectives of carers and professionals working with adults with Intellectual Disabilities.

Method

Semi-structured interviews were conducted with 20 adults with Intellectual Disabilities asking about their personal experiences around internet use, social media and online safety. Four focus groups were also conducted; one with safeguarding professionals working with people with Intellectual Disabilities, one with paid carers, and one with family carers. The final focus group brought all of these stakeholders together. All focus groups discussed issues around internet use, online safety, barriers to internet use and opportunities available online for adults with Intellectual Disabilities.

Results

Thematic Analysis was conducted on transcripts of recorded interviews and focus groups. Some of the emerging superordinate themes include a) "Risk Taking & Restrictive Practices", including risk mediation, positive risk taking and empowerment for adults with Intellectual Disabilities; b) "Victims & Perpetrators", exploring how adults with Intellectual Disabilities can

be both the perpetrators, and victims of online harm; c) “Online Identity” looking at personal development and growth, and how people present themselves online, find friendship, love and community. Conclusions are explored in the context of the evolving use of the internet and online experiences of adults with Intellectual Disabilities, and the factors that influence these experiences.

Co-Designing with People with Learning Disabilities: an architectural perspective

Menatalla Kasem,

Welsh School of Architecture, Cardiff, United Kingdom

Architecture deals with a wide spectrum of users, to fulfil these varied perspectives on using buildings, the users can participate in the design process as experts/experienced users. This includes people with learning disabilities, as they can be incorporated into the design process as experts in accessibility and disability issues. Unfortunately, this is not the norm, people with learning disabilities are usually spoken of rather than spoken to or with. Their unique cognitive profile, and limited communication skills, have resulted in a lack of studies involving them. Consequently, their experiences are not heard, and their needs are unexplored. Yet, to truly reach inclusive designs their participation in the design processes is necessary as it has proven of real value to the general design knowledge because they can indicate a wide range of accessibility issues. Therefore, there is a need to change the conventional model of the design process to be transcended to involve their perspective concretely.

This study evolved through the researcher's -an architectural professional and educator embedded in the third sector- interaction with the learning disability community, supported by a co-researcher with a learning disability. It describes a two-phase study with people with learning disabilities as active participants, the first was semi-structured interviews, and the second was walking interviews. They aimed to 1) understand their preferences and pattern in using public buildings, 2) understand the impact of different architectural elements and spatial characteristics on them, 3) investigate how they experience their environment, 4) and explore the barriers they face in public buildings. Both phases were facilitated by a co-researcher with a learning disability, who also ensured the accessibility of all the participant facing materials. This facilitation of the conversation between user and designer is vital, as it helps designers gain a greater understanding of the diverse accessibility needs.

12-05-2023

15:15 - 16:35 - Work and employment II - Skills, innovation and self-employment Hilton Nordica meeting room I /

Everyday activities and employment among young adults with intellectual and cognitive disabilities with an interest in playing online games

Kristin Alfredsson Ågren, Helene Lidström, Dimitris Michailakis

Linköping university, Norrköping, Sweden

Few adults with intellectual disability (ID) and cognitive difficulties have a regular or adapted employment. Playing online games has become an alternative occupation for some. There is a striking lack of knowledge on how active online gaming can affect the possibility of getting a job. The aim of the study was to describe (a) how these young adults perceive their conditions and abilities to get closer to the labor market and (b) to identify various needs of support to enhance their possibilities of a job.

The research method was participatory design. Eleven young adults with ID and cognitive difficulties with an interest in playing online games were interviewed using a semi-structured instrument to capture their self-perceptions of performance in everyday activities. A set up of the outcome was discussed in three focus groups to deepen the understanding of the participants' competence from online games and need for support.

The results showed that the participants expressed a feeling of hopelessness related to getting and keeping a job. The obstacles they identified are e.g., difficulties in planning and organizing the everyday day activities in general. Further, they perceive a lack of opportunities to influence the design of their work situation. Playing online games is usually perceived as positive as it enables social interaction, gives opportunities to solve and complete tasks, and creates routines. The participants highlight that online games also provide new knowledge, such as managing digital devices, moderating games, and improve their English language, which should benefit their employability.

A core finding in this research is that the target group must be given the possibility to participate in the design of their work situation to make it sustainable over time. The digital competence from online gaming should be valued to a greater extent and regarded as an asset for employment.

Disabled people's participation in innovation: an Icelandic social innovation project

Sandra Halldórsdóttir, Stefan Hardonk

Centre for Disability Studies, Reykjavík, Iceland

Participation of disabled people in employment is a domain in which inequalities continue to exist. Research has demonstrated different types of barriers to work inclusion and some scholars have pointed out the importance of questioning the meaning of work and the way in which it is organised. In response to this call and taking into account the increasing emphasis placed by western industrialised countries on innovation as foundational to economic development, a study was conducted in Iceland to understand the possibilities as well as barriers in relation to disabled people's participation in innovation. The study was done using qualitative methods. Interviews were held with 12 individuals, including disabled people, disabled and non-disabled innovators, experts in innovation and representatives from disabled people's organisation. Data analysis rested upon a thematic approach, aimed at identifying opportunities as well as barriers. The findings showed that while few disabled people are currently active in innovation, there is a shared interest by many actors involved. Also, barriers at different levels need to be addressed in order to realize the opportunities in innovation for disabled people. In this presentation we will discuss these findings and present a social innovation project that was developed in response to the study findings in collaboration with major stakeholders. The project aims to support disabled people who wish to engage in their own innovation as well as those who wish to participate in other innovators' projects.

Self-employment among people with disabilities: establishment motives, barriers and opportunities in Sweden

Maria Norstedt, Per Germundsson

Malmö University, Malmö, Sweden

People with disabilities that lead to reduced work capacity continue to be positioned far from the labor market in Sweden. Self-employment can offer a flexibility that enables establishment in the regular labor market for this group. At the same time self-employment involves high demands and risks. In many countries people with disabilities start their own business as a strategy to get access to an exclusionary labor market and the group is overrepresented among self-employed. In Sweden however, the proportion of self-employed persons with disabilities is smaller compared with other countries. Support for self-employment among people with disabilities is articulated both in the UN convention and in European union policies, but such discourses are lacking in Swedish labor market- and disability policy.

Our study is a qualitative exploration of interviews with self-employed people with disabilities (focusing on deafness, sight impairment, neuropsychiatric impairment and mobility impairment), representatives from the Public Employment Agency, and other collaborating actors. The self-employed persons' experiences have been reported in our recently accepted article to *SJDR*. Our presentation at NNDR includes some of the main findings from the whole study as such, where the aim was to identify and understand establishment motives and factors that influence the conditions for business ownership by people with disabilities that entails reduced work capacity in the Swedish context.

The different establishment motives identified in the study are *flexibility and self-determination, economic motives, negative work experience, contributing something, and being an entrepreneur – an identity positioning*. Moreover, the results show that self-employment offers an opportunity to participate in working life and thereby entails recognition and social inclusion. The identified barriers include a physical inaccessibility of the environment, prevailing norms regarding entrepreneurship and inflexible, contradictory and hardened regulations concerning support and social insurances.

Barriers to work inclusion: does social construction of skills matter?

Stefan C. Hardonk,

University of Iceland, 102 Reykjavík, Iceland

Research into work inclusion has provided insight into the importance of employers' perceptions of disabled people as potential employees. Several studies have pointed out the gap between employers' generally positive views of disabled people and their actual hiring intentions and behaviour. Understanding this discrepancy is important to develop new ways of addressing the mechanisms that keep employers from valuing disabled people as employees. To contribute to this stream of scholarship, this study examined how employers construct skills requirements for jobs and how they perceive the skills of disabled people as potential employees. Qualitative interviews were conducted with 18 persons responsible for recruitment and hiring in organisations of different sizes and in different economic sectors in Iceland. Participants were asked questions about important skills for different types of jobs within their organisation as well as their experience with and expectations of disabled

employees. Data analysis was based on a constructivist grounded theory approach and emphasis was placed on understanding employers' perceptions in relation to the concept of social construction of skills. Findings reveal on the one hand that social constructions of skills based on expectations of non-disability underlie seemingly neutral ways of describing skills requirements. On the other hand, employers' perceptions of disabled people's skills appeared to be susceptible to stereotypical interpretations and problematisation. Participants also invoked requirements external to the organisation as challenging for disabled employees. In conclusion, the study suggests ableism in the social construction of skills requirements and in the perception of disabled employees' skills.

12-05-2023

15:15 - 16:35 - **Inclusion III - Disability activism and rights 2** Grand Hotel - Ásgarður /

A world where you could just live your life. Role of utopias in disability activism

Reetta Mietola, Amu Urhonen

University of Helsinki, Helsinki, Finland

Whilst activism has unarguably taken up new forms due to wider changes both in media landscapes and in political participation in general, it has been argued that even these 'new activisms' resonate with the idea of social movement due to collective vision and view of change. This challenges accounts where recent changes have been considered as having mainly negative effects, leading to individualisation of activism and fracturing of social movements. In our research project focusing on activism and disability movement in Finland we have aimed to respond to this academic debate by doing empirical research on disability activism asking what kind of changes can be found in focuses, claims and forms of activism and what kind of social movement is formed by the ongoing political action. At the same time as our data suggests that the recent and ongoing shifts in activism might not be as dramatic as this academic debate might lead us to think, we have noted some signs of fracturing that could actually be connected to blurring of collective vision and direction of action. Some of the disability activists we have interviewed have found it difficult to articulate the future conditions that they hope to achieve; in some accounts there is very loose – if any – links between goals and forms of activism (what is being done). This has led us to ask on the other hand what these contradictions tell about the current context of political action (and challenges raising from this), on the other what is and could be the role of utopias in disability activism and disability movement. In our paper we will address these questions by drawing on our research data consisting of interviews of Finnish disability activists and a dataset produced in a utopia workshop arranged by our project.

Constructing the passive recipient of social support. The role of efficiency assessment in defining the relation between disability organisations and their members

Pekka Koskinen,

University of Helsinki, Helsinki, Finland

During recent decades, civil society organisations receiving public funding have been exposed to increased reporting duties and efficiency assessment. Civil society research has pointed out how the increased accountability policies from funding agencies threatens the autonomy of civil society organisations. Increased accountability demands a new kind of reporting expertise from the organisations, which puts them in an unequal position according to their resources to report their activities. In addition, reporting duties can subtly steer the actions of organisations towards activity that fits harmoniously with the report templates. However, research analysing how the increased accountability alters the relation between organisations and their members are yet scarce.

In order to prove their effectiveness to the funding agencies, disability organisations have to demonstrate how the target group has benefited from the organisations' activities. By analysing the meaning of target group inherent in the efficiency assessment reports and policies, I will argue that the increased accountability also affects how disability organisations are supposed to think about and approach their members and constituent groups. In contrast to civil society ideals of organisations representing their members' interests and voice as democratic citizens, the efficiency assessment constructs disabled people as passive recipients of social support provided by the disability organisations.

It's My Life! Decision – making experiences of young disabled people in Ireland & Article 12 UNCRPD.

Clíona de Bhailís,

Centre for Disability Law and Policy, University of Galway, Galway, Ireland

Disabled people are routinely denied the right to make basic decisions about their lives including decisions about where to live, medical treatment and finances. Disabled children and young people can experience a 'double jeopardy' - failing to meet both adult and non-disabled norms – making them particularly at risk of being excluded from decision making. Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) there is an increased recognition of disabled people's right to make decisions based on their will and preferences and use support. However, what this means for young disabled people and their experiences remain largely unexplored.

This paper will explore the range of barriers young people with disabilities may face in participating in decision making and having their will and preferences respected. To do so it will draw on data collected on the decision-making experiences of young people, aged 15 – 20, in Ireland with lived experience of a range of disabilities. The paper will discuss the findings across two overarching themes – *Relationships & Attitudes* and *Support & Reasonable Accommodation* – and the changes required to law, policy and practice to address the issues uncovered.

The Exclusion of Persons with Disabilities from Undertaking Jury Service: International Human Rights Law as a Tool to Challenge Discrimination

Charles O'Mahony ,

University of Galway , Galway , Ireland

The eligibility of persons with disabilities for jury service is an issue that is receiving greater attention with public interest litigation challenging the exclusion of persons who experience deafness or hearing loss from jury service. This presentation examines this exclusion using two case studies from Ireland and Australia, which illustrate the challenges and opportunities in reforming law and policy in this area. The presentation then turns its attention to the UN Convention on the Rights of Persons with Disabilities (CRPD) and considers how the CRPD can be effectively used by persons with disabilities, disabled persons organisations and other stakeholders to challenge law and policy that excludes persons with disabilities from undertaking jury service on an equal basis with others.

12-05-2023

15:15 - 16:35 - Culture and history II - Medieval Disability Studies: Challenges and Commonalities ÖBÍ 2 - Sigtún 42 /

Canst thou not minister to a mind diseased?

Christina Lee,

University of Nottingham, Nottingham, United Kingdom

The past decade has seen major advances in research into both physical and mental impairment in the Middle Ages. It is commonly agreed that this period needs to develop models and methods which are useful in discussions of disability, where literature portrays a worldview that is distinct and different from our own (Crocker, Tirosh and Jakobsson, 2021). In recent years scholars, such as Emily Kesling, have demonstrated that medical texts in Early Medieval England are produced in monasteries and thus mirror concepts of healing closely embedded with Christian ideas of healing. Central to it is the idea that spiritual health is a significant outcome of healing, but that 'health' in itself is not possible. Complete health is only attainable in Heaven and by default any healing in this life can only restore functionality. For individuals with disability this will have had some ramifications since it removes the suggestion that there is a normative health.

Real life experiences, however, may have not mirrored such attitudes and occasionally the view that patience should ignore conditions in this life may have been harmful. Here patients may have had to access other forms of care. In this paper I explore whether literature offered forms of understanding and resolving depression. While medieval writers knew about depression, they were not always sympathetic, meaning that people suffering depression may not have been able to access adequate support or even experience stigmatisation, because religious ideas of health do not allow for it. The necessity to function as an individual in a society that experiences crisis on a regular basis through war and famine may have also reduced the ability to receive help.

This paper considers literature's role in describing trauma and anxiety and the function of text in healing in Early Medieval England and select Old Norse poems.

Constructions of Disability in Hrafn's saga Sveinbjarnarsonar

Natalie Van Deusen,

University of Alberta, Edmonton, Canada

Hrafn's saga Sveinbjarnarsonar, a *samtíðarsaga* with hagiographic overtones, is known as the saga of Iceland's first physician. In the saga, which was written between 1230 and 1250, tells the story of Hrafn Sveinbjarnarson (ca. 1166-1213), there are a number of examples not only of Hrafn treating individuals with various injuries and diseases, but also of Hrafn's encounters with individuals with physical, sensory, and mental difference.

This paper examines the saga from the perspective of critical disability studies, and attempts to demonstrate that the saga is also a valuable source for understanding how disability was constructed in medieval Iceland. It argues that the medieval Icelandic understandings of disability was one that was informed by medicine, religion, and social factors, and that that this saga especially demonstrates the intersection of these various perspectives on the disabled body and mind.

Disability, exile, trauma and healing. A reading of Grettis saga

Torfi H. Tulinius,

Háskóli Íslands, Reykjavík, Iceland

The characters of Grettis saga are not individuals that can be analysed separately, as if they were the patients of a psychiatrist. One must rather understand the saga as a meaningful whole, which attempts to make sense of an existential situation familiar to the author and her or his intended audience. The three longest narrative developments in the saga of Grettir concern Öundur tréfótr, Grettir himself and his half-brother Þorstein drómundr. The valorous Öundur, deprived of one of his legs, is forced to an impoverished exile in Iceland. His great-grandson Grettir has a troubled relationship with his father which the saga associated with an inability to control his impulses. Growing up, Grettir proves his valour, but his lack of restraint is compounded by his traumatic encounter with the revenant Glámr. Unjustly outlawed, he is unable to prove his innocence because of his impulsiveness. He lives most of his life as an outlaw, finally executed by his enemies when his leg has been severely injured by magic. His killer has fled to Constantinople and joined the Varangian guard. Grettir's half-brother Þorsteinn follows him there and avenges his brother. Thrown into a dungeon, Þorsteinn sings to save his fellow prisoners from desperation. His voice attracts a noble woman who has him freed and whom he weds afterwards, the two finishing their lives as holy hermits.

The tragedy of Grettir is given a deeper meaning by the two other stories. As a narrative, the saga expresses an understanding of the relationship between exile, trauma and difficulties of the soul, but also of how the voice, and poetic expression in general, can lead to love and spiritual healing.

WHAT WAS STOLEN? - The medieval vocabulary of unexpected bodily transformation

Ármann Jakobsson,

Háskóli Íslands, Reykjavík, Iceland

In Morkinskinna, we find a short anecdote where the son of a noble woman loses his mind, as if he is “hamstoli” but is later cured in a dream by the joint kings of Norway. Icelandic prose narratives from the 13th and 14th centuries are replete with instances of physical ailments that are interpreted within the frame of metamorphosis, often not merely corporeal but also spiritual. In this paper, the Old Norse lexicon of such bodily and mental transformations will be closely examined, such as the words *hamrammr*, *hamslauss* and *hamstoli*.

12-05-2023

15:15 - 16:35 - **Indendent living, self-determination and citizenship**
Grand Hotel - Hvammur /

The GAS-VI Guide: a tool to evaluate independent living supports

Gemma Diaz-Garolera¹, Maria Palliser¹, Judit Fullana¹, Carolina Puyaltó¹, Montserrat Vilà¹, Maria Josep Valls², Ana Rey¹, Maialen Beltran¹, Montserrat Castro¹

¹ *University of Girona, Girona, Spain*

² *University of Lleida, Lleida, Spain*

The Convention on the Rights of Persons with Disabilities establishes their right to live independently and to be socially included. Specifically, each person has the right to decide where and with whom to live, to access to support services and personal assistance, and to fully participate in the community. Therefore, a transformation towards a community-based model is crucial. However, it requires support professionals planning personalised supports and focusing on each person's needs and desires, making adaptations as such needs and desires change or evolve. The GAS-VI Guide (Guide for the Evaluation of Independent Living Supports) allows professionals and people with intellectual disabilities to assess the extent to which the supports provided are aligned with the approaches of the Convention. There are two versions of the Guide: one for support professionals, and another one, in an accessible format, for people with intellectual disabilities. Both have been validated by professionals and people with intellectual disabilities. The structure of the Guide is based on 4 dimensions: Individual, Interpersonal, Organizational and Community. Each of them includes different indicators, and these contain different items about the supports provided. These items are valued from 1 to 5 by the professional, and from 1 to 3 by the person who receives support. Responses from professionals can be compared with those of people receiving support. Then, some guidelines and strategies aimed to improve the support in each of the dimensions are suggested. Using the GAS-VI Guide can encourage people with intellectual disabilities to actively participate in decisions about the support they receive, as well as promote processes of evaluation and improvement of the quality of existing support services. Over the next two years, a pilot test will be developed with support service users to continue improving the Guide and to be able to extend its use.

Navigating social infrastructure: exploring aspects of community in everyday living environments from the perspective of people with psychiatric disabilities

Maria Fjellfeldt¹, Ebba Högström², Urban Markström³, Lina Berglund-Snodgrass⁴

¹ *Dalarna University, Falun, Sweden*

² *Blekinge Institute of Technology, , Sweden*

³ *Umeå University, Umeå, Sweden*

⁴ *Swedish University of Agricultural Sciences, Alnarp, Sweden*

In the post-deinstitutionalized era, one objective is to provide people with psychiatric disabilities the opportunity to safe and dignified living in the community. This article explores aspects of community - in terms of social infrastructures including people and place - in everyday living environments, experienced by people with psychiatric disabilities. A photo voice study was conducted. Twelve persons living with psychiatric disabilities participated. Data was analyzed using the concept of social infrastructures including (1) service and facilities, and (2) social organization, to explore aspects of community in participants' everyday life. The results showed that participants experienced (i) their own house as a safe place crucial to recovery, and (ii) authorities (e.g. social services and others) as stressful parts of their everyday living environment. Social organization was experienced in places free of charge, such as libraries, parks, Fountain houses, and communities on the internet. Animals were emphasized as a vital part of everyday social infrastructures by several participants. Poverty was a circumstance affecting accessibility to preferred everyday life social infrastructures. One specific dimension of social infrastructure in people with PD everyday life was the staff working with housing support. These staff affected people with PD's everyday living environments in several ways, both emotional (as a sister), bodily physical (support to eat) and physical material, both in the home (support to clean) and in a wider area, (e.g. participating in meetings with authorities). In conclusion, places and people were partly experienced in other ways than conventionally discourses display: participants experienced e.g. internet, the darkness and the deep woods as "safe" places, while social service offices, the police and the psychiatric care were experienced as extremely stressful places. Participants navigated social infrastructure where some elements were people and places wished for, while other people and places were compulsory and certainly not wished for.

Social workers' perspective: identification and assessment of victims of intimate partner violence with cognitive disabilities in Sweden.

Filippa Klint¹, Åsa Källström¹, Sofie Adaszak¹, Lisette Farias Vera²

¹ *Örebro University, Örebro, Sweden*

² *Karolinska Institutet, Stockholm, Sweden*

Background: In Sweden, social workers are responsible for identifying, assessing, and supporting victims of violence among people with and without disabilities. Research has shown that people with cognitive disabilities are more likely to become victims of intimate partner violence (IPV) than non-disabled people. Some reasons for the high rates of victimization that people with cognitive disabilities have reflect a dependence on others in everyday activities, limited access to adapted communication, and lack of education about the victimization of IPV for this group among professionals and social workers. Yet, there are

no official disability-adapted assessments to support this work. Very few studies explore the type of adaptations needed to identify and assess the risk of violence against this group. Therefore, this study aims to explore how social workers identify and assess victims of IPV with cognitive disabilities.

Method: An explorative and qualitative design using focus group interviews with five groups of social workers was conducted. Each group contained three to five social workers employed either at a municipality's social services or NGO and having experience working with people with cognitive disabilities or IPV. Group discussions were led through six topics prompting participants to describe their experiences working with people with cognitive disabilities who are victims of IPV.

Results: Preliminary results point to both challenges and good examples of the practices concerning identification, assessment, and support of victimization among people with cognitive disabilities focusing on the resources at different types of organizations to meet the needs of this group. Local adaptations of government-recommended assessment tools such as adding picture support or verbally elaborating definitions of IPV were common. Some difficulties in cooperation between and within institutions were also described.

Conclusion: Final results and conclusions will be presented at the NNDR research conference in May 2023.

Ethical dilemmas at group homes - Professional perspectives of the complexity of supporting self-determination according to disability rights

Sofia Bergholtz,

Malmö University, Malmö, Sweden

Background and purpose: Misconduct at group homes with special services for disabled persons has recently attracted attention and created headlines in Swedish media. That all people, regardless of abilities, should have the opportunity to decide over their own lives is something that the vast majority agrees and declared by the UN Convention on the Rights of Persons with Disabilities. Self-determination and participation are also strongly emphasized in Swedish national social legislation. But what are the obstacles that cause the staff at group homes fall short of these goals? When the respect for all people, and the right to self-determination, participation, equality, and equal living conditions in some cases turns into indifference and cynicism that could lead to severe abuse?

Method: This study analyses the point of view of personnel who work directly with people with intellectual disabilities and autism. The data consists of six focus group interviews with staff from two group homes in a major Swedish municipality. Each group participated in three focus group interviews, with 1-4 weeks in between for the interviewees to reflect upon certain situations. The thematized dilemmas will be interpreted from social constructionist and a disability rights perspective.

Conclusions and implications: Preliminary findings suggest that dealing with ethical dilemmas constitute the greater part of the staff's day-to-day work. Group homes are a complex working environment that often involves one-to-one situations that require micro-decisions. In this paper I want to visualize how the residents' opportunity for self-determination depends on the staff's handling of ethical dilemmas. How dilemmas force the staff to balance on the fine line between motivation and manipulation, between guiding and

to force. The problem is particularly visible in situations of stress, risks of danger or inconvenience that also affect group housing neighbors, visitors, or staff.

12-05-2023

15:15 - 16:35 - **Inclusion IV - Meet the Editors** Grand Hotel - Útgarður

- Moderator: Angharad Beckett, University of Leeds and International Journal of Disability and Social Justice

****Meet the Editors Session** Open Access Publishing in Disability Studies**

Angharad Beckett,

University of Leeds, Leeds, United Kingdom

Meet the Editors Session

Open Access Publishing in Disability Studies

Joint Chairs of Session: Professor Angharad Beckett (University of Leeds and IJDSJ) and Professor Leslie Swartz (Stellenbosch University and SJDR)

This Special Session (ideally 1.5hrs) will be led by representatives of the following Open Access journals:

[African Journal of Disability](#)[Canadian Journal of Disability Studies](#)[Disability and the Global South](#)[International Journal of Disability and Social Justice \(IJDSJ\)](#)[Scandinavian Journal of Disability Research \(SJDR\)](#) The format will be as follows:

5 minutes: Welcome

30 minutes panel discussion and Q&A regarding 'Open Science' or 'Open Scholarship' initiatives in Disability Studies and the role of Open Access journals in democratising access to knowledge. Representatives from each of the journals will reflect on the motivation/mission of their publications, the opportunities and challenges involved in open access publishing. We will consider 'where next' for open scholarship in international, interdisciplinary disability studies?

10 minutes comfort break and opportunity for participants to browse and take-away information about the journals involved in this event

45 min panel discussion and Q&A on 'Writing for Academic Journals'. This session will be targeted towards early career researchers, but is open to all. The journal editors will seek to demystify the process, share tips on productive practices, what makes a good article and how to manage not only the intellectual challenge of writing for publication, but also the time-management needed and the emotions of the review process. Their objective is to make the process less daunting, build confidence and boost enthusiasm for writing and submitting to journals such as those represented in this Session.

12-05-2023

15:15 - 16:35 - **Policy and theoretical perspectives V - Self-determination and supported decision-making** Grand Hotel - Gullteigur B /

Social workers' perceptions and judgements regarding guardianship and supported decision-making

Roni Holler¹, Shirli Werner²,

¹ *Hebrew University of Jerusalem, Jerusalem, Israel*

² *Hebrew University of Jerusalem, Jerusalem, Israel*

Social workers' perceptions and judgements regarding guardianship and supported decision-making

Background: Following recent criticisms on guardianship, Israel has recently amended its Legal Capacity Law and developed less restrictive alternatives, mainly supported decision making (SDM). Despite their cardinal role, social workers' perceptions and recommendations regarding guardianship and SDM have received little scholarly attention. This study examined social workers' perceptions and the underlying factors influencing their decisions in matters of guardianship and SDM.

Methods: A mixed method design was applied: a) Semi-structured interviews were conducted with 27 social workers working in this field. b) A factorial survey was completed by 328 social workers who rated the need for guardianship or SDM in relation to vignettes containing four dichotomous independent variables: Type of impairment (intellectual vs. mental), Level of decision-making support needed (low vs. high), individuals' preference (refuses vs. agrees to guardianship), and familial support (available vs. unavailable). .

Results: Findings from the qualitative data show that whilst social workers acknowledged the shortcomings of guardianship, they nevertheless perceived it to be vital. The factorial survey reveals that social workers were more likely to recommend guardianship when the person depicted in the vignette was labeled as having an intellectual disability, needed support in decision-making, lacked familial support, and agreed to guardianship. In addition, social workers who had not heard of the SDM reform, and who held positive attitudes toward guardianship tended to recommend guardianship appointments. The qualitative data enhances our understanding of these factors and the complex and diverse ways in which they come into play.

Discussion: Findings are discussed in relation to the Status, the Functional and the Relational approaches to legal capacity. Key practical implications for both policy and social work practice will be discussed to better realize the right of people with disabilities to autonomy and legal capacity.

The perceptions and experiences of adults with intellectual disability regarding supported decision-making: A qualitative study

Hannah Casey, Deirdre Desmond, Laura Coffey

Maynooth University, Maynooth, Ireland

Background: Supported Decision Making (SDM) has been identified as an effective method of decisional support for adults with intellectual disabilities. In the Irish context, there are few resources for adults with intellectual disabilities and their carers to help them apply the principles of SDM in everyday life. The aim of this research was to ask Irish people with intellectual disabilities what they value most in carer support in everyday decision-making.

Methods: Twelve adults recruited through two disability services in the Republic of Ireland participated in focus groups in July and October 2022, as part of a wider research project including professional and family carers. Discussions were audio recorded and transcribed. Transcripts were analysed using Reflexive Thematic Analysis (Braun & Clarke, 2021).

Results: Preliminary themes and subthemes identified include 1. A Strong Support Network (Giving Options, Trust, Listening), 2. Struggles in Decision-Making (Barriers and Inhibitors, Financial Worries, Worries About the Future) and 3. Valuing Independence. This tentatively suggests that adults with intellectual disabilities value their independence in decision-making, as well as having carers who listen, and are willing to centre their personal goals and wishes. Inhibitors to decision-making were often external, such as staff changes, resource availability, or carers making decisions without consultation. All indicated they would welcome a guide for decision-making to use with supporters; they suggested the guide should be easy to understand and include key issues such as managing money and planning trips.

Conclusion: Adults with intellectual disabilities value decisional freedom, independence, and having supporters familiar with their goals. A decision-making guide should be user-friendly, accessible, and address key stakeholder concerns. Further research on this topic is currently being conducted with staff and family carers. These results will also inform the creation of a decision-making guide for use by adults with intellectual disabilities and their supporters.

Moving in to live independently? Perspectives from young women with intellectual disabilities in Norway

Anne Linn Midttun¹, Anita Gjermestad², Inger Marie Lid²

¹ *Hå kommune, Bryne, Norway*

² , ,

Self-determination in services for persons with intellectual disabilities increased with the de-institutionalisation in the early 1990s. However, after the year 2000, research shows that self-determination again decreased through, for example, building larger residential housing and offering fewer activities. This article aims to present the perspectives of four young women as they moved from their parents' into municipal housing.

Inspired by participatory research, we planned and conducted four dialogue conferences together to generate knowledge about these women's process. The four women were able to decide themes for the conferences, location, participants, timeframe and refreshments. We analysed the conferences together orally.

Findings show the complexities of citizenship and self-determination in this context and how the four women feel ambiguity between being ready to live on their own and at the same time wanting support from staff. Findings also show that structures and repressive technologies live on in the services, restricting the women's self-determination and room for action.

The findings are analysed by the academic researchers through a lens of rights-based citizenship and the human condition understood as vulnerable and interdependent.

The following research questions will be discussed: What perspectives do four young women with intellectual disability have on the process of transitioning to live independently, and what challenges related to self-determination and citizenship are evident?

Nind, M. (2014). *What is inclusive research?* Bloomsbury Academic.

Mackenzie, C., Rogers, W., & Dodds, S. (2014). Introduction: What Is Vulnerability, and Why Does It Matter for Moral Theory? In C. Mackenzie, W. Rogers, & S. Dodds (Eds.), *Vulnerability : new essays in ethics and feminist philosophy*. Oxford University Press.

Söderström, S., & Tøssebro, J. (2011). Innfridde mål eller brutte visjoner? Noen hovedlinjer i utviklingen av levekår og tjenester for utviklingshemmede. In.

Perspectives of Supported Decision Making from Self-Advocates, Supporters and Advocates

Christine Bigby¹, Craig Sinclair², Julia Duffy³, Ilan Wiesel⁴, Terry Carney⁵, Shih-Ning Then³, Jacinta Douglas⁶

¹ *La Trobe University, Melbourne, Australia*

² *University of New South Wales, Sydney, Australia*

³ *Queensland University of Technology, Queensland, Australia*

⁴ *The University of Melbourne, Melbourne, Australia*

⁵ *Sydney University, Sydney, Australia*

⁶ *La Trobe University, Melbourne , Australia*

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities generated debate about supported decision making. The pace of practice change, service and legal reform about supported decision making has differed between service sectors and disability groups. This study crossed boundaries including aged care and disability, and the diversity of people with cognitive disability involved in supported decision-making. It explored cross sector perspectives about supported decision making, its benefits, key elements and implementation issues.

Seventy-nine people participated in an online focus group or interview. Participants included people with intellectual disabilities, dementia and acquired brain injury and mental health issues, family members, service providers and advocates. A semi structured interview schedule guided discussion about topics including, understandings of supported decision-making, contexts of supported decision-making, types of supporters, standards and strategies for quality assurance. Digital recordings were transcribed verbatim. Grounded theory methods were used to develop and refine codes across all transcripts and to collapse codes into broader categories.

Perspectives about supported decision making fell into five categories; a contested concept, furthering the exercise of rights, diverse traditions of decision support, advocacy or decision support, and obstacles and facilitators. Key elements of a pan disability cross sector framework to implement supported decision-making were identified - universal principles, taking account of diversity, interrelationships with other systems, compensating for inequities, best practice models, capacity building, oversight, mechanisms for advanced planning, co-leadership by people with cognitive disabilities, adequate funding and strategies for building social connections.

Supported decision making encompasses, diverse contexts, support, supporters and decisions. Despite diversity, views converge about its benefits, its role in social change and difference from advocacy. The findings form the basis for development of principles and essential elements of a framework for supported decision-making and obstacles to be addressed for success of comprehensive reform.

12-05-2023

15:15 - 16:35 - **Disability and the lifecourse II - Old age** Hilton Nordica meeting room H /

Towards better understanding of needs of older persons with hearing disabilities – a fight against ageism and misconceptions

Anniina Lavikainen,

University of Helsinki, Helsinki, Finland

Disability studies has engaged in interaction with Deaf studies, with focus on Deaf persons, their complicated relationship with hearing disability and the status of Deaf people as a cultural and lingual minority. Less is known regarding persons with hearing disabilities who use spoken language as their mother tongue. With three different data sets, policy, media and survey data (n=1054), I bring forward the heterogeneity of older persons with hearing disabilities and expose their societal position in Finland. Included in the research are persons over 50 years of age with congenital and acquired hearing disabilities.

Unilateral descriptions of older persons with hearing disabilities are challenged with critical reading of policy and media documents. The intersections of age and disability are made visible. Regarding the Finnish disability act, the policy makers argue older persons with hearing disabilities as a problem for “real” disabled persons, because of the incidence of hearing loss in the older population. However, they fail to recognize the internal heterogeneity of persons with hearing disabilities and how, for example, the severity of hearing loss influences the situation. Media portrayal confirms the unilateral picture, even though the media portrayal is a bit more nuanced.

The survey data challenges many traditional views related to hearing loss. 80 percent of the respondents do not regard using hearing aid as shameful. Survey data makes visible that older persons with hearing disabilities have less assistive technology, for example majority of retired persons have only one hearing aid whereas those in working-age have two hearing aids. Even though 96,7% of respondents have hearing aids or implants, 94,4% of them tell that they experience hearing difficulties often or occasionally. Open answers make visible

the structural and environmental barriers that cause the hearing difficulties and exclude older persons with hearing disabilities from societal arenas.

Transition to Retirement of Older People with an Intellectual Disability - Staff Descriptions of the Process and Roles

Sirpa Granö¹, Sonja Miettinen², Elisa Tiilikainen³, Elina Kontu¹

¹ *Tampere University, Tampere, Finland*

² *Finnish Association on Intellectual and Developmental Disabilities, Espoo, Finland*

³ *University of Eastern Finland, Kuopio, Finland*

Our study examines how staff in housing and day activity centres describe the transition of people with an intellectual disability (ID) to old-age retirement, and the different actors' roles in it. The data comprises the staff's written responses to open-ended questions included in an online questionnaire. The data were analysed using content analysis, followed by further analysis using the concept of script.

We identified two main scripts in which the staff outline the transition process. According to the person-centred script, the role of the person with ID in transition is an actor with initiative and the staff are seen as enablers and supporters. In the system-driven transition script, the role of the person with ID is a passive object adapting to changes, while the staff seems to implement routines and organisational instructions.

The system-driven script requires numerous instructions for different situations, whereas the person-centred transition progresses by listening to the person with ID and resolving matters on a situational basis. This study shows that there is inequality among ageing people with ID. Their possibility to make decisions from retirement depends on which script is followed in their municipality's disability services and service provider organisation.

Living with dementia in Nigeria: Everyday tactics and strategies used in adjusting to memory loss

Elizabeth O. George,

VID Specialized University, Oslo, Norway

Everyday activities such as navigating one's environment and community, calling to check up on loved ones, making dinner, shopping, or carrying out religious rituals can become challenging for people with dementia. When dementia makes ordinary and mundane areas of a person's life challenging, they may find solutions for themselves to remain in control of their lives. This paper draws on findings from a doctoral research project which was carried out in a low-income Yoruba community in Nigeria and focuses on the everyday experiences of people living in Nigeria. It highlights everyday strategies and tactics that people with dementia and those around them employ in adjusting to life with reduced cognitive functions. The fieldwork, which lasted for a period of 5 months and drew on the African relational perspective to consider the roles that relationships – to other people, non-human subjects, and things – play in shaping the everyday experiences of people living with dementia in this community, reveals uniqueness and creativity involved in the ways that people with dementia – and their networks – adjust to everyday life with dementia and continue to play important

roles in their families and communities. This paper will focus on some of these unique and creative strategies employed.

PEOPLE WITH DEMENTIA AS PEOPLE WITH DISABILITY

Henna Nikumaa,

University of Eastern Finland, Joensuu, Finland

Objectives

The aim of the study was to scrutinize the autonomy, agency and legal capacity of people with dementia.

Methods

The data consists of individual interviews with 16 people with mild dementia (interviewed twice) and 25 group interviews of 98 professionals (mostly different social and health care units, legal aid and local register offices). The data was analysed using abductive content analysis.

Results

People with dementia associated and combined the experiences of autonomy with the experiences of equality. They reported how their cognitive disability is not seen as a real disability and felt inequality compared with other groups of different diseases or disabilities.

Professionals reported how the current practices of interpretation and the application of social service and disability legislation in Finland often put people with dementia in a worse position compared to other groups with different diseases or disabilities. Cognitive challenges of people with dementia are not usually regarded as a disability, which would justify the entitlement for disability services for people with dementia.

Both interviewed groups had noticed that the UN Convention on the Rights of Persons with Disabilities is not applied enough to people with dementia.

Conclusion

Dementia is a leading cause of disability for older people. However dementia is not usually recognised as a disability in the context of policy, practice or disability legislation. Disability legislation should be the framework through which the right to services is secured for people with dementia. People with dementia are often treated unequally, as compared with those that have other disabilities, with respect to access to disability services. In the European context, which is characterized by relatively strong public welfare provision and quite comprehensive national disability legislation, people with dementia still find themselves in an unequal position and experience discrimination in terms of access to services.

12-05-2023

15:15 - 16:35 - **Childhood disability III - Rethinking disability and human rights** Hilton Nordica meeting room F /

- Moderator: Inger Marie Lid, VID Specialized University

Exploring the relationship between Citizenship and Universal Design

Inger Marie Lid,

VID Specialized University, Oslo, Norway

This paper seeks to lay out the epistemological and normative foundations for universal design as a human rights concept and a strategy that supports equal access to citizenship. Universal design is an international strategy aimed at equal access included in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The concept addresses barriers faced by persons with disabilities, emphasizing that design influences access. As a general strategy for dismantling disabling barriers, it is meant to be implemented in different local and national contexts.

In this paper, the epistemological foundations of universal design are examined. The paper begins with a brief historical background on disability and human rights. The comparative dimension of the CRPD is discussed in light of disparity, and the normative claim supporting diversity and equal status is discussed. Taking a critical realist approach to disability and equal access, the concept of universal design is situated within this theoretical paradigm. Based on this epistemological analysis, the paper argues that political and institutional mechanisms are crucial for supporting the implementation of universal design. As a strategy facilitating equal access for all citizens, universal design involves a macro, meso, and micro level when implemented in different local and national contexts.

I argue that the implementation of universal design must involve all these political (administrative) levels in order to be efficient. The CRPD is an instrument that can be used to increase the agency of persons with disabilities; awareness of that agency helps to avoid the risk of social determinism when explaining disability history. For the CRPD to strengthen the agency of persons with disabilities, the transition from words in a document to practical politics is fundamental. As such, the implementation of the CRPD is important, as it entails translating universal articles into practical politics in different political contexts.

Conditions for religious citizenship for people with intellectual disabilities: cases from Norway and Slovakia

Inger Marie Lid,

VID Specialized University, Oslo, Norway

The notion of citizenship is elusive and manifold, in both general and scholarly usage. An especially fruitful way to conceptualise citizenship is to emphasise it as belonging to a particular community (not necessarily a nation-state), which enacts certain rights and obligations from their members, all of whom actively participate on equal footing. Religious citizenship is a varied and multilevel concept. On the level of the nation state, it may be

understood as the constitutionally guaranteed freedom to worship and participate in religious practice, alone or in community with others. On the level of religious organisations and communities, it can be seen as granting people the status of full members of these organisations on an equal basis with others. In the research we

present in this chapter, we consider religious citizenship largely from the perspective of conditions that enable people with intellectual disabilities to actively practise religion and participate in the lives of their religious communities, on their own terms and on an equal basis with their non-disabled fellow citizens.

Mad Citizenship

Michael Rembis,

State University New York University at Buffalo, Buffalo, United States

This paper focuses on the efforts of people who identify as users and survivors of psychiatric services and people living with psychosocial disabilities to combat the largely unchecked expansion of western, global north bio-psychiatry and take control of their own treatment and care. People who identified as users, survivors, and psychosocially disabled played a critical role in drafting the CRPD. Many of those same activists, as well as a growing global community of psychosocially disabled people, are using the CRPD to protect their human rights and to establish themselves as leaders of and participants in mounting efforts to shift the expanding global mental health movement away from bio-psychiatry toward peer support and other, more holistic, justice oriented, sustainable interventions.

The Space of Accessibility and Universal Design

Edward Steinfeld,

State University New York University at Buffalo, Buffalo, United States

Accessibility is a compensatory strategy conceived to prevent discrimination while universal design seeks to change the consciousness of those who create the built environment to address a broader conception of the human body. Both concepts are united by the common goal of social inclusion, and both are necessary to achieve that goal. The CRPD explicitly emphasizes the former but implicitly acknowledges the value of the latter. The physical environment is a dynamic and charged reality incorporating and integrating conceptions of space, perceptions of space, and the lived experience space. A case study of the implementation of accessibility and universal design in the United States helps to understand how these three aspects of space contribute to the production of disability and the realization of social inclusion. The main lesson from the case study is that space, like disability, is culturally determined and thus the path toward social inclusion will vary from one cultural context to another.

12-05-2023

15:15 - 16:35 - Education II - Intersectional perspectives and educational context Grand Hotel - Muninn /

Education at the Intersection of Disability and Race

Allyson Eamer,

Ontario Tech University, Oshawa, Canada

This in-progress interdisciplinary research takes an intersectional approach to exploring the school experiences of racialized children with disabilities (e.g. a developmental or intellectual disability, autism, or a vision, hearing, speech, orthopedic or neuromuscular/mobility impairment) in the Canadian K-12 education system. We consider the political, cultural, financial and institutional barriers that impact inclusion in classroom activities and equitable educational supports being offered to - and utilized by - minoritized families to ensure their child's educational potential is being met. The overarching goal is to identify through surveys and interviews with parents, children, educators and therapists, any disparity between the level/kinds of educational supports being accessed by minoritized children with a disability and the level/kinds of educational support they are entitled to by international human rights law, the provincial disability act and school board policies. Through identifying the reasons for the differential, we will make recommendations to parents and policy makers for addressing it. Additional objectives include: 1) documenting how minoritized parents of children with disabilities understand and exercise their rights with respect to accessing supports for their child's education, 2) documenting teachers' perspectives with respect to the level and kinds of supports available, the process by which they are accessed and the role of the parent in this process, 3) helping professionals involved with families (teachers, educational assistants, principals, social workers, therapists, child development specialists) better understand the barriers facing minoritized parents in the school system, 4) helping minoritized families understand the network of professionals involved in their disabled child's life, and to understand their child's right to educational supports, 5) making policy and procedural recommendations that would improve communication between professionals and families; and between professionals and culture-specific agencies, as well as encourage funding formulas that allow for culture-specific staffing enhancements.

Perceptions of ultra-Orthodox students who participated in social involvement programs towards people with disabilities

Edith Blit Cohen,

Hebrew University Of Jerusalem, Tel Aviv, Israel

In Israel the scope of social involvement programs of students in the academy has increased in recent years. In addition, there has been an increase in the number of ultra-Orthodox people applying for academic studies. "The Lev Academic Center" is an academic-Torah institution in Jerusalem, where students study for bachelor's and master's degrees, mainly in technological fields and health sciences, and sacred studies. The study was a qualitative research based on 15 in-depth semi-structured interviews with ultra-Orthodox students who during their studies participated in a social involvement program with people with disabilities.

The program promotes the rights of people with disabilities in ultra-Orthodox society in Jerusalem. The research questions related to the attitudes of the students regarding their professional identity, interpersonal aspects, social-civic attitudes, and their integration into the multicultural society in Israel. They were also asked about the challenges they encountered during their volunteerism. The findings revealed three central themes: 1. The perceptions of expertise that the students developed through their experience as volunteers in the field of care for special populations. 2. Volunteering as a shaper of consciousness and as a platform for personal development. 3. Some students' desire to be actively involved in changing and improving policies regarding people with disabilities. This study suggests that student can bridge the gap between academia and their communities, and serve as agents of knowledge and change towards both sides. Their community involvement benefits both them and people with disabilities. There is a need for an inclusive policy that promotes the participation of diverse students in community involvement programs with people with disabilities as a means of reducing stigma, professionalization and social engagement.

Environmental factors and supports for school participation in students on the autism spectrum

Kate Simpson, Dawn Adams

Griffith University , Brisbane, Australia

Background – There is an increasing number of identified students on the autism spectrum attending school. Despite an inclusive school policy, children on the autism spectrum are reported to participate less in school activities, experience higher rates of school refusal and underperform academically compared to their non-autistic peers. Identifying environmental factors that may help and hinder student participation, and strategies to encourage school participation are important to inform practices to support students on the autism spectrum.

Method - Parents and teachers completed the school subscale of the Participation and Environment Measure for Children and Youth (PEM-CY) on 128 children (8-17 years) on the autism spectrum. Parent and teacher responses to environmental facilitators and barriers to participation were compared. Content analysis was conducted on the parent and teacher identified strategies used to support student participation.

Results- Parents and teachers both rated the cognitive and social demands of the typical school activities as a barrier to participation, and both the safety and the physical layout of the school as a facilitator to participation. However, there were responder differences across all items with parents more frequently rating items as a barrier than teachers. Parents more frequently identified resources as available compared to teachers. Parents most frequently reported advocating for their child with school personal and preparing their child for the school environment as strategies supporting participation. Teachers focused specifically on strategies used to support student learning, including adapting or adjusting the tasks and providing instructional supports.

Discussion –The findings from this study, highlight the importance of obtaining multi-informant responses to better understand what may help or hinder the participation of students on the autism spectrum. These differing perspectives highlight the importance of parents-teachers collaboration to support students on the autism spectrum participating in a school setting.

Collaborative, Responsive Behaviour in Book-Reading: Children with Down syndrome & Hearing Impairment

Lill-Johanne Eilertsen¹, Oddvar Hjulstad², Romy Regina Prochnow³, Sigrun Slettner⁴

¹ *Signo Resource Centre and University of South-Eastern Norway, Andebu, Norway*

² *University of South-Eastern Norway, Drammen, Norway*

³ *Eikholt Resource Centre, Drammen, Norway*

⁴ *Signo Resource Centre, Andebu, Norway*

Background: This paper presents a study from a larger project called 'Building communication and participation in school activities: Interactions involving pupils with Down syndrome and hearing impairment (DS-HI)'. Amongst important areas and situations children spend time at, the school has a significant role. In addition to academic education, it also frames a large portion of children's social life. Children's peer interaction is often characterised as spontaneous, joyful, sometimes containing complex rules and rapid changes. Communication challenges caused by developmental or linguistic disorders might interfere with the fluency of the activity, or the shared experience of mutual understanding in general. This paper explores the collaborative labour involved in establishing alignment between a child with Down syndrome in combination with hearing impairment (DS-HI) and a hearing peer without DS or HI, during shared interactive book-reading activity in an inclusive educational setting.

Method: The project group visited schools, observed teaching classes, meals and free play, and video recorded situations of naturally occurring interactions. A shared book-reading activity was chosen for deeper analysis. The study draws on the Conversational Analysis (CA) framework, applying multimodal interaction analysis adjusted for Sign Language. Data are in Norwegian.

Results: The situated shared book-reading is regulated by interaction rules. A pattern of collaborative, responsive behaviour in where the children align to each other's initiatives is identified within these interaction rules.

Discussion and conclusion: The shared book-reading format has a scaffolding function in the interaction. The findings illustrate how a typically developing peer is able to align to the sensory and cognitive capacities displayed in the child with DS-HI, and how this facilitates co-created meaning-making in the interaction.

12-05-2023

15:15 - 16:35 - Policy and theoretical perspectives IV - Regulatory, financial, and other political barriers for realising the right to personal assistance (PA) in Iceland, Sweden, and Norway. Grand Hotel - Gullteigur A /

- Moderator: Egil Skogseth, Uloba - Independent Living Norway
- Moderator: Jessica Smaaland, STIL
- Moderator: Jonas Franksson, STIL

Law and policies that affect disabled persons in Iceland

Erna Eiríksdóttir, Hjörtur Eysteinnsson, Rúnar Björn Herrera Þorkelsson

NPA miðstöðin (Independent Living Center Iceland), Reykjavik, Iceland

Personal Assistance (PA) in Iceland was first implemented in 2012 as a trial. The goal was for PA to become the main service for disabled people in Iceland with gradual steps taken away from institutional care. To achieve that goal a financing scheme was introduced between the municipalities and the state running from 2018 until end of 2022. The scheme laid out commitments to increase PA contracts on a yearly basis until there would be 172 contacts by the end of the term, however there are only 93 contracts.

The state has failed to fully finance their part of the scheme and the municipalities have fought to not fund PA in accordance with the wage agreement for PAs under the presumption of PA services being too costly. These issues persist beyond the year 2022 and the waiting list for personal assistance is only getting longer. Even though the legal right to PA has been secured the future of PA is not secure.

Autonomy of municipalities is seemingly strong as each municipality has their own regulations and evaluations system regarding PA.

Since the ratification of CRDP in Iceland in 2016 we've seen some positive changes, such as article 19 being implemented into law in 2018. With the 38/2018 law came regulations regarding PA and specifically regarding waitlists for PA.

We will use quantitative research regarding the PA-scheme from participating municipalities, Ministry of Welfare, and data reports from The Centre of Disability Studies Iceland.

Our presentation will highlight the need for Iceland to legalize the CRDP and what steps the parliament must take to implement it completely. We will focus on PA and the importance of policies based on the social model instead of the medical model. Lastly, discuss how the autonomy of municipalities can have harmful effects on human rights.

Policies for securing disabled Norwegians the right to personal assistance

Egil Skogseth,

Uloba - Independent Living Norway, Drammen, Norway

A consensus has been developed among national politicians in Norway, that local municipalities must annually deliver a substantial increase in the number of active Citizen-controlled personal assistance-schemes (CPA). Parliament ratified CRPD in 2013, and passed a CPA-reform in 2014, securing some groups an individual right to CPA. Prior to this, government published a forecast on the effects of the reform, expecting that the amount of disabled Norwegians with CPA would increase between 3400 and 6900 in seven years. Has national policy in Norway contributed to a substantial growth in the amount of disabled with citizen-led personal assistance (CPA)?

Methodological approach

Analysis of statistical data concerning the CPA-scheme from The Norwegian Directorate of Health, Statistics Norway, evaluation reports on CPA trial projects and CPA-policies.

Key CPA-policies

CPA was introduced by disabled activists as a radical alternative to traditional services. It became a part of Norwegian welfare policy in 1994. Local municipalities could apply for a new state grant to finance training of disabled work leaders and their assistants. From 1995 till it was terminated in 2013, the grant could also be used to finance assistance. In 2000, Parliament amended The Social Service law, including CPA, and defining it as a variant of traditional social services. From 2000 on, local municipalities had to offer CPA. First to adults who could become work leaders for their assistants, and In 2005, to all disabled who need assistance. In 2012 CPA was redefined as a health and care service in The Health- and Care Act.

Key findings: Seven years after the reform was implemented in law, in 2021, the amount of active CPA-schemes had increased by 988. The annual growth was twice as large in 2000-2011 compared to 2012-2021.

Legislation of personal assistance – 30 years and forward

Jessica Smaalund, Jonas Franksson

STIL, Stockholm, Sweden

The Swedish parliament voted for the legislation of personal assistance 30 years ago. Since then, Sweden has considered being the leading country regarding personal assistance. However, it is debatable whether this is still true.

Personal assistance in Sweden came about thanks to a strong independent living movement during the late 1980s and early 1990s. In a project with the city of Stockholm, the members of STIL proved to politicians and other decision-makers that personal assistance delivered better quality service for both users and employees at the equilibrated cost of home care not led by the users themselves.

However, the legislation has constantly been questioned. Several investigations and law changes have taken place over the years. The courts also developed a common law that has changed the enforcement of the legislation. Initially, one did not have to have any specific needs to qualify for the service. Today it is considered that mostly medical needs should determine whether someone is entitled to personal assistance. As a result, people who previously had personal assistance are no longer qualified.

STIL has been working against this development for the past 15 years. In collaboration with researchers, we have produced reports that, among other things, show what happens to people who lose their assistance. We have also confirmed that personal assistance still provides the best quality for the money. Even the UN has criticized Sweden for not following the CRPD and for the state's backward development.

Our presentation will summarize the development of the legislation of personal assistance in Sweden and the motives behind it. We will also discuss the pros and cons of the scheme from a user perspective. Finally, we will address the changes needed for Swedish legislation to comply with the CRPD.

Whose life is it anyway?

Laila Bakke,

Uloba - Indendent Living Norway, Trondheim, Norway

The past five years Uloba has documented that Norwegians who need of assistance often can not enjoy of their civil rights. They don't "own their own life", in the sense that the local municipality, to a large extent, can decide how they can live their lives.

The legislation sets the framework for the type of assistance that is given to people with disabilities. The Health and Social Services Act law instructs the local municipality to manage assistance services. Bureaucrats decide whether the citizen can receive the assistance in his own home, or whether he must move to an institution.

Until 2015, citizen-controlled personal assistance-schemes (CPA) was regulated by the Social Services Act. In 2012, the scheme was enshrined in the Health and Social Services Act. This has influenced how the municipalities manage CPA, and which framework conditions citizens with assistance needs have. We are seeing a shift from a social model to a medical model in the way CPA is managed. We see a greater focus on health and less assistance to be able to live as active citizens of society.

Methodology

Surveys aimed at citizens in need of assistance, license analyses and in-depth interviews with case managers in health and welfare, literature review in the field.

12-05-2023

**17:00 - 17:40 - Keynote address by Marjorie Aunos with
International Sign Language** Grand Hotel - Gullteigur A/B /