Inclusion, Participation and Human Rights in Disability Research - comparisons and exchanges

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Dissecting strategies for creating inclusive societies in twelve western countries, going beyond accessibility concepts and achieving universal usability

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Since the mid-1960s, the concept of accessibility has evolved into a key notion for making modern welfare society inclusive for large groups of people regardless of their potential cognitive and functional abilities. In the beginning, the concept primarily targeted physical requirements for the built environment (e.g. floor level, spatial configuration, illumination, and signage). In the evolution of the concept in Sweden, accessibility has achieved both secondary and tertiary complementary meanings that refer to strategies for dismantling obsolete attitudes about people with disabilities and for ensuring that artefacts and media are useable by users with a diverse range of abilities, limitations and characteristics.

By the end of the 20th century, many countries used accessibility or similar concepts (e.g. access, barrier-free design, design for all, inclusive design, accessible design) in creating inclusive welfare societies. In 2006, the UN Convention Rights for People with Disabilities (CRPD) associated universal design thinking (UD) to this quest. This paper presents findings from a study on the implementation of accessibility and universal design and similar concepts in twelve countries in three geo-economical spheres. The research material was assembled by key word searches, interviews and questionnaires. Swedish conditions were used as a matrix for creating comparative analyses. The result suggested that national strategies for promoting accessibility and universal design depended upon the chronical debut and the cultural context.

From a Swedish perspective, at least three possible avenues for further development of the concept of accessibility for the 21st century are identified: definition of conceptual theorems, collection of exemplary models and practices, as well as increased use of ICT. We propose to host a session in which 2-3 experts from the countries studied discuss and analyse the conclusions of the study, and give further insights into the realisation of an inclusive welfare state with full potential for participation regardless of age and disabilities.

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Egyptian Disability Movement: Are Voices Heard and Policies Impacted?

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Egypt represents a meeting point of the North, South, Africa and Asia. Egypt's population reached around 92 million, 15% of whom are disabled.

The aim of presenting this study " which assesses the current situation of the Egyptian disability movement and DPO's using Cairo as a case study" is to give a historical background on the disability movement and how it impacted policy framing and development process concerning disabled people in Egypt. It will also highlight the effects of the major political events embodied in the strikes and protests prior to and during the 25 January 2011 revolution, on disabled people and how these circumstances enhanced the emergence of new disabled people alliances and organizations.

The research methodology of the study combined both qualitative and quantitative methods to make the best use of the data available. Structured interviews and focus groups were used as the main tool for data collection. The combination of both descriptive and explanatory research types were also applied to give an in depth understanding into the strengths and weaknesses of this movement. The target group of this study mostly has different types of impairments; different formats were applied to ensure appropriate accommodation of all participants.

So the presentation design will tackle the following themes: A brief historical background on Disability Movements Worldwide such as IDA and EDF and how these acknowledged disabled peoples' needs and called for their rights. Following this, a demonstration of the current situation of disability movement in Egypt, before and after the revolution, will be presented in order to understand the extent to which it affected the situation of disabled people in terms of rights, policy and practices.

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Finally the study recommendations offer needed mechanisms to enhance the capabilities, organization and effectiveness of the disability movement in Egypt, so they can appropriately advocate for their rights.

Keywords: disability movement, Egypt, policies, Egyptian revolution, alliances, DPOs

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A minority within a minority: Being transgender and having an intellectual disability

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Introduction and Aim: Sexual identity and sexual expression are integral parts of the life of a person, and persons with disability are no exception. However people with disability face prejudice, stigma and discrimination when expressing non-heteronormative sexual identity. This paper explores the experiences of a young person with intellectual disability who identifies as Transgender in a Maltese socio-cultural context.
Method: A qualitative research method was employed to explore the lived experiences of the participant using Interpretative Phenomenological Analysis (IPA).

Results: The research identifies lack of awareness and acceptance of persons with disability who identify as LGBTQI, amongst family members, professionals and service providers, as well as within the local community. These agents lead to fear and ignorance that contribute to the barriers encountered by persons with disability when expressing their sexual identity.
Discussion: Being a minority within a minority contributes to further infringements of human rights of persons with disability who identify as LGBTQI and hence from the possibility of full participation in society. Thus, persons with disability require further support from organisations that promote the rights of the LGBTQI community. More awareness and education about intersectionality is required to uphold the rights of persons with disability who identify as LGBTQI.

Keywords: Sexuality, Gender, Disability

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The emergence of the public problems of invalidity and blindness at international scale (1918-1939).

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This statement aims to explain how the questions related to infirmity in general (disability related to the war, blindness, deafness, etc) are built as public problems at international scale during the interwar period. I want to analyze the role of many protagonists who contribute to the appearance of these public problems on the international public stage : intergovernmental organizations (League of Nations, International Labour Organization, Health Organization), ONGs, representatives employers', trade-union representatives. We will study the transnational advocacy networks specialized on the questions related to infirmity, the rights which they defend. We will also study the negotiations and the conflicts which emerge between all the concerned people. How do the transnational advocacy networks manage to impose some questions related to infirmity on the agenda of the international organizations ? With wich arguments ?

To answer these questions, we carried out research in the archives of the League of Nations, and the International Labour Organization, but also in the associative press and the acts of international congresses.

This research enabled us to note that only the questions related to disabled ex-serviceman, victims of work and blinds are truly studied in-depth by the international organizations (League of Nations, ILO) during this period. Only the rights of some categories of disabled people (disabled ex-serviceman, victims of work, blinds) are legitimated by international recommendations during the 1920's and 1930's. Other questions (deafness, mental deficiency) are not studied in-depth, in spite of the mobilization of some ONG and governmental representatives. Some factors slow down the internationalization of the rights of the various categories of disabled people: the weak legitimation of the rights of these categories of disabled person on the national scale; the weak support of ONG; the opposition of the representative employers'; the weak support of the governments.

Keywords: history, disability movements, rights, problems, international organization

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Sexuality: a measure for citizenship and inclusion

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Session proposal

A number of research studies have demonstrated disabled people's struggles to be acknowledged as sexual beings in a culture where dominant ideals of sexuality often exclude non-normative bodies and minds. According to a global report from the World Health Organization (WHO) and the United Nations Population Fund (UNPF) the sexual and reproductive health and rights of disabled people are often disregarded. One reason for these struggles and lack of attention towards sexual issues concerning disabled people has to do with the general taboo surrounding the theme; with consequences such as insufficient competence for relevant professionals, and lack of representation, or rather misrepresentation, in social policy, media and culture. Sexuality is a broad subject, covering issues such as sexual and reproductive health and rights (SRHR), sexual identities and orientations, and sexual engagament. An important related issue concerns the potential professional support needed for disabled people to be able to express their sexualities as desired or to achieve ad adequate sexual health and well-being. This session includes presentations with different focus on sexuality issues from different contexts and concerning different disabilities, in order to present the broadness and complexity of sexuality as a social phenomenon. All presentations discuss sexuality as a measure for health, well-being and human rights – in other words: as a measure for citizenship and inclusion in any society striving to be inclusive and accessible to people of all abilities and sexualities.

Presentations:

- Julia Bahner, doctoral student, Dept. of social work, University of Gothenburg, Sweden. Sexuality: a risk or a right? Conceptualisations of sexual expression by personnel in disability services

- Jack Lukkerz, lic. phil., Malmö University, Sweden. An empty arena – on attitudes to and experiences of sexuality education among special school and habilitation service staff in Sweden
- Dr. Claire Lucille Azzopardi Lane, Dept. of Disability Studies, University of Malta. A minority within a minority: Being transgender and having an intellectual disability

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Sexuality: a risk or a right? Conceptualisations of sexual expression by personnel in disability services

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Most people adhere to an understanding of sexuality as a fundamental human need, which includes the right to sexual expression and sexual health. However, the sexuality of disabled people is often disregarded, in cultural contexts as well as in disability services, where personnel often lack adequate competence to be able to handle sexual expression in a non-discriminatory way. This presentation is based on a research study concerning the thoughts and experiences of personnel in Swedish personal assistance services about sexual expression in their work with mobility disabled people. Specifically, the concept of sexual facilitation is discussed, i.e. the assistance potentially needed for assistance users to be able to express their sexuality as desired. Individual interviews were conducted with 15 personal assistants and three focus group discussions were conducted with ten managers. The informants worked mainly with municipal and private service providers. Results show that the specific characteristics of Swedish personal assistance services influence how sexual facilitation is conceptualised and handled. For example, since sexuality is not mentioned in the rights-based law governing disability services and its preparatory work, or in other types of regulations and guidelines, several personnel either do not expect having to work with the assistance users' sexuality, or are very insecure about how to handle upcoming situations. Furthermore, the law that the services are based on, aiming to give the possibility for individualized services, leads to a great discretion for personnel in handling sexuality according to their personal values and norms, which are sometimes discriminatory. Hence, the silence of sexuality in disability policy, combined with a lack of organisational support for learning about and working with sexuality, may lead to assistance users being unable to express their sexuality in the desired way, which in the long run, may reproduce disabling structures hindering equal citizenship and participation in society. **This abstract is suggested to be part of the session Sexuality: a measure for citizenship and inclusion.**

Keywords: sexual facilitation, personal assistance services, independent living, sexual citizenship

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Immigration and disability: Minority families with disabled children

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Issue

Families from non-western countries are for various reasons seldom included in research on families with disabled children, and there are few separate studies about families with "double" minority background. This paper discusses how families with disabled children understand disability and how they cope with their situation. Do disabled people from ethnic minority groups face the same type of challenges as the majority population in their daily lives, or do they meet special barriers due to factors like culture, religion, language, prejudice or racism? Do they have other or additional problems because of their status as ethnic minorities? What are their experiences from interaction with the service system?

Methods

- Qualitative interviews with 50 families, living in eight different municipalities in Norway. The majority of the parents are first generation migrants from different countries: Sri Lanka, Pakistan, Somalia, Iraq, Iran and Lebanon.

- Observations of their children in kindergartens and schools.

- Qualitative interviews with teacher and other professionals.

Results

The study indicates that the situation of migrant families with disabled children is simultaneously similar to and different from families in the majority population. Special challenges are for instance: problems with language and communication, lack of information about disability and the service system, being met with prejudice or discrimination and having practical problems defined as culture. There are great needs for improving the service system in order for professionals to be able to meet the needs of these families. Improvements have to be made with regard to: written information in the preferred language of the families, systematic use of interpreters, better coordination of services and greater awareness among professionals about how these families both are similar to and differ from other families.

Keywords: Immigration, Minority families, Children, Service system, Language, Culture

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*Speaker

Special educational needs – assessment and categorizing processes in an international perspective

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Issue addressed

The aim of this paper is to explore how disabilities are 'socially constructed' within the educational system. Moreover, conceptual frameworks for diagnostics as well as assessment models are being discussed. Relevance is given as an inclusive educational system gives the frame. It's driven by the question if categorization through special educational needs is relevant, useful and appropriate?

Method

A comparative perspective of two countries, Germany and Sweden, is the starting point for understanding and comparing different diagnose and categorizing processes and professional responsibilities. The data entails international and national publications and steering documents.

Analysis/ results

The results implicate that the use of different assessment measures as well as resources leads to a variation in practice regarding differentiation and adaption in learning processes.

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Gruppenbild mit Mensch mit Behinderungen. Studying life-course of people with " rare disabilities " through institutional records

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Studying the French category of " rare disability " (Winance, Barral, 2013) we analysed 60 records of people for which the assistance of two of the 4 "national centres for rare disabilities" was required. We made there also numerous observations and had interviews with the specialists that met these persons with multiple deficiencies. But, as the author of the famous Gruppenbild mit Dame (B´oll, 2001), we didn't meet the persons themselves: we are working on a choir description of peculiar subjects. In our presentation we would like to discuss some features of this record analysis.

Studying records which often have more than hundred pages leads to collect a large amount of information about one person, with various points of view: expertise of the specialized centre, medical records, educative records, mails conversation with family or professionals, generally over several years. We propose to analyse how and to what extent this large amount of objective data is a chance to study meticulously the work of the national centres for rare disabilities, institutional rationales and individual life-courses.

Sometimes the subject makes also his or her way through the record we are studying: graphic traces of a disabled child, pictures, sometimes written message to the professional, emotions of the parents or the professional, in one case a personal diary. These unexpected meetings are a strong reminder of the existence of a subject beyond the objective reports on him or her. They are of importance for the research: it shows that the role of the centres is also to rehabilitate dismissed persons as subjects - notably by building new frames of interaction (Goffman, 1986).

By these reflections we want to discuss how the subject is rendered by objective and subjective materials gathered in the records. This leads to a last question. What do our voice as researchers add to these choir description ? Are we silencing weaker voices ?

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*Speaker

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'The issue is about her "social capacity"': exploring 'risk' as another category of difference in intersectional analysis in disability research.

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Drawing on ethnographic fieldwork between 2011/2012, this paper is an intersectional analysis of how social categories - 'learning disability'; 'mental capacity'; 'woman'; 'ethnic minority' - were operationalized in a learning disability service. Research involved observation of 'everyday' practice – multi-professional risk assessments, team meetings, needs assessments - and interviews with professionals. In England and Wales the Mental Capacity Act 2005 (MCA) established a framework for assessing cognitive capacity, classified incapacitated adults as uniquely susceptible to risk, and enshrined a legal duty to 'protect' them from 'harm'. Within the MCA, cognitive incapacity and risk are mutually constitutive, with the aim being to 'safeguard' the adult concerned. In a Foucauldian sense, 'mental capacity' is another social category because it is defined in law and professionals have powers to identify corresponding individuals. The findings from this research show that professionals operated with an informal conception that 'learning disability' and 'mental (in)capacity' were associated categories, which together put service users at risk and strongly impeded their ability to protect themselves. Women learning disabled service users provoked particular anxieties about their 'sexual vulnerability' or 'promiscuity'. While hitherto researchers have highlighted the intersectionality of 'learning disability' and other social categories (Guvtasson et al, 2005) this paper suggests that risk is another mark of differential treatment. Being a woman taking 'unwise' and 'risky' decisions about your sexual relations could lead professionals to question your 'social capacity' and cognitive abilities to deal with everyday uncertainties. Relatedly, certain cultural practices and beliefs were considered risks to service users because they led service users and/or their families to make questionable decisions about their lives, including sexual relations.
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*Speaker

Are the so-called Students with Special Educational Needs scarcely prosocial by nature or by culture?

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Introduction Several studies on inclusion underline an increasing difficulty for the Italian school system in offering an adequate response to the differences that characterize each student while maintaining high levels of curricula standardization. Within a system tending to normalization, even socio-relational skills are conveyed and read through an ableist perspective, with the activation of inevitable processes of marginalization towards those students who diverge from default standards. This research, conducted from February to October 2015, is intended to evaluate if and to what extent the levels of pro-sociality of students identified as having Special Educational Needs (SEN) are different from those of their "not SEN" classmates. These data are analyzed in reference to inclusive processes activated inside the examined schools. Type of data used Quality / quantity - based Subjects 168 students (seven classes from four different schools) Tools • Students: Prosocial scale (Caprara, 2005); Peer nominations (Caprara, 2012); Sociometric Test (Moreno, 2007). • Teachers: Inclusion Questionnaire (Bocci, Travaglini, 2014); interviews and focus groups. Analysis NVivo; SPSS. Results As regards the students, a connection between prosociality and learning levels emerges, with a tendency to the marginalization of SEN students. This situation is not perceived by teachers, who do not seem to notice such critical issues within the school system. Main references Ferri, B. (2015). Inclusion for the 21st Century: Why We Need Disabilities Studies in Education. Italian Journal of Special Education For Inclusion, 2, pp. Caprara, G.V. (Ed) (2014). Educare alla prosocialità: teoria e buone prassi. Torino: Pearson. D'Alessio, S., Medeghini, R., Vadalà, G. & Bocci, F. (2015). L'approccio dei Disability Studies per lo sviluppo delle pratiche scolastiche inclusive in Italia. In R. Vianello & S. Di Nuovo (Eds.). Quale scuola inclusiva in Italia? Oltre le posizioni ideologiche: risultati della ricerca. Trento: Erickson.

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Rights in Transition: The Experiences of Young Deaf People

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Young deaf people have the right to access education, employment and training on the same basis as their peers, to express their views in decision-making processes, and to be provided with the necessary support. These rights have been reaffirmed by the United Nations Convention on the Rights of Persons with Disabilities (2006). Moreover, the Committee on the Rights of Persons with Disabilities has recently produced a draft General Comment on the right to inclusive education (2015). How well these rights are being met in practice however can be indicative of the efficacy and/or challenges of implementing human rights discourse.

This paper will explore the disjuncture between rights discourse and rights practice through the lens of educational transitions. It will draw on findings from a recent research project which aimed to identify the difficulties that deaf and hard of hearing young people experience in accessing post-16 education, training and employment opportunities. Using a rights based approach, encompassing a young people's advisory group, interviews with young people and interviews with professionals, the paper will provide insight into the hidden contradictions that can emerge.

The paper will suggest that, despite the oft-cited commitment to 'disability rights' and 'inclusive education' in policy discourse, the experiential reality of young people's transitions is characterised by complex practices of discrimination and exclusion. These concerns are being exacerbated by broader transitions in social policy and the impact of austerity on support provisions for young people.The paper will ultimately argue that there is a need for a more nuanced understanding of rights implementation if young people's rights to education, employment and training are to be effectively realized.

Keywords: Transition, Rights, Deaf: Young People: CRPD, Education

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Rights-Holders under the UNCRPD: Challenging Definitions of Disability in Human Rights

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The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has been welcomed with much vigour and celebration. Significant as the first bespoke human rights treaty for people with disabilities, we have now entered a new era where focus must shift to implementation and monitoring of States obligations; that is, from 'rights talk' to 'rights action'.

This paper will provide an empowering but critical analysis of disability rights discourse in the context of the CRPD. It will explore the innate conservatism and flaws of 'rights talk' when it comes to disability, and its inherent contingency upon the perceived characteristics of rights-holders. For no other population group in society are rights subject to such a range of both explicit and implicit qualifications. This 'smoke and mirrors' character is particularly evident with respect to conceptualisations of 'individualised support', 'resource availability' and 'reasonable accommodation' and their respective emphases upon the extent of individual impairment or 'deficit' rather than upon the extent of institutional or structural deficit.

Moreover, effective claiming of some of the CRPD's rights may require active self-identification as 'disabled' – on the State's terms – in order to access services or appropriate support. By means of illumination, this paper will draw on a documentary analysis of definitions of disability in State party reports and the CRPD's concluding observations to date. This paper will ultimately highlight how rights for disabled people may come to be experienced as disempowering and conditional, effectively leading to a form of 'rights disqualification'

Keywords: Rights, CRPD, Definitions, Reasonable Accommodation

*Speaker

Realising the Participation Rights of the Disabled Child: realistic goal or wishful thinking?

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The right of disabled persons to participation does not stop at being included in mainstream education, in open employment, in services and facilities open to the general public, and in the community at large. This right also includes the right of the disabled person to participate in decision-making processes. Furthermore, it is a right granted to all disabled persons, including children. This paper first sets out what the participation rights of the disabled child are according to the CRC and the CRPD. It then considers to what extent these are realised in practice. The data used is taken from extant empirical research carried out in European countries about the participation rights of the disabled child in health, education, home life and relationships. An analysis of this research indicates that, while there are plenty of examples of good practice, we are still far from a situation where we can claim that disabled children's participation rights are being comprehensively realised. The factors contributing to this situation are identified, among them the fact that the creation of opportunities for the disabled child to exercise their participation rights effectively depends on the adults' awareness of how to go about creating such opportunities, on the extent to which they believe that disabled children can exercise their participation rights, and ultimately on what these adults understand to be participation rights. Based on this analysis, the paper contends that for the participation rights of the disabled child to become a realistic goal across the board, rather than remaining mostly a case of wishful thinking, we must first of all reach a consensus as to what these rights actually are. This paper therefore concludes with a proposed definition of the participation rights of the disabled child.

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[*]Speaker

Invisible identities: A critical analysis of intersections of gender, culture and disability in the Maghreb

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Women with disabilities face multiple layers of discrimination; they are discriminated against on the basis of their disability as well as of their gender. In addition, women with disabilities constitute a diverse and heterogeneous group – many of them may face additional prejudice and stigma due to their race, ethnicity, sexual preference, age and other aspects of who they are and how they live. This multiple discrimination is explicitly recognized in the UN Convention on the Rights of People with Disabilities which in its article 6 obligates State parties to "take all appropriate measures to ensure the full development, advancement and empowerment of women." This presentation will examine intersections of gender, disability and culture, drawing from 75 interviews with girls and women with disabilities 12-45 years-old, living in urban, suburban and rural settings in Algeria, Morocco and Tunisia, to identify sociocultural barriers faced by women with disabilities in the Maghreb region and their impact on the enjoyment of basic human rights, particularly the right to social protection and an adequate standard of living. Interviews were conducted in the summer 2015 by interviewers who were themselves women with disabilities, atter attending a specific training. With the informed consent of the participants interviewes were taped and thenfully transcribed and analysed using the software NVivo 10 to support content analysis.

Results show that the intersection of these women's positionalities entail particular challenges, struggles and expectations that cannot be fully understood as the result of one-directional or cumulative processes of inequality and oppression and should therefore be seen as a new reality that may compound and deepen social exclusion. Yet the narratives collected show also multiple strategies of resistance of these women, which need to be identified and understood in order to renew, deconstruct and reconstruct our knowledge about women with disabilities in the Maghreb.

Keywords: women with disabilities, human rights, Maghreb

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Of some pitfalls and deadens of participatory applied research: A critical reflection on common principles and techniques of reform within disability service networks

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Although researchers and practitioners are forever seeking to improve the state of partnership within disability networks, a state of non-collaboration often persists between client, family, and professional stakeholders. Using the Saskatoon Partnership Project as a case study, the current article explores some of the challenges associated with conventional approaches to participatory research and reform (Boudreault & Kalubi, 2006). The authors reflect on the limitations of propositional, participant-driven, parsimonious, problem-centered, and majority-based reform tactics and question the capacity of these devices to engender meaningful change within complex social institutions. By interrogating the pitfalls and deadens of their own research, the authors provide some insights about the challenges associated to the reform of large disability service networks. They also propose alternative avenues of research and reform in order to improve partnership within such networks and argue that a more critical, dialogical, and pragmatic (Habermas, 2011/1968; Ladmiral, 2011/1990) approach is capable of revealing unrecognized nodes of resistance and novel opportunities for service improvement.

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Remaking disability in China: The Little People's Kingdom in Kunming (Yunnan Province, China)

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In this presentation we contextualize 'The Little People's Kingdom', an entertainment park in which people of short statue are performing song and dance twice a day in an open air show, near Kunming in Yunnan Province, China. We first narrate the perspective of the founder Mr. Chen and staff-members, followed by the narratives of Little People themselves. We then situate the phenomenon in the context of China in its emergence as an open and modern country, in the context of its cultural heritage, and existing cultural research on Little People. We will conclude by discussing the question whether the Little People's Kingdom should be described as a freak show. In the discussion of this paper, we will argue that the Little People's Kingdom can be understood as a case of cultural industry, revolving around 'smallness' which involves both innovation and continuity of Chinese culture. We will also argue that a good understanding of 'The Little People's Kingdom' and the remaking of disability in China requires notions of philanthropy, perspectives on human rights protection, and business potential in the context of China's continued development as a modern state. It would also require an analysis of the formation of the gaze, without suggesting that the Little People's Kingdom is merely a freak show.

Keywords: Little People, China

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Which theory of disability does transhumanism presuppose ?

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The aim of this talk is to discuss from both a cultural and critical disability studies perspective the way people with disabilities are viewed in the emerging field of transhumanism. According to transhumanist scholars like Ray Kurzweil, director of engineering at Google, or Nick Bostr'om, director of the Future of Humanity Institute at Oxford University, the NBIC convergence should give to human beings the possibility to experience in the near future a radically new human condition 2.0. The use of biotechnological means should indeed release human beings from natural death, diseases and disabilities which affect human species for more than 200 000 years. On the basis of a cultural disability analysis of popular and academic literature, films and media, I will first show how people with disabilities are depicted within the transhumanist culture. By relying on such cultural overview, I will then address the following issue from a critical disability studies perspective: why are life experiences of people with disabilities mostly viewed by transhumanists as experiences of human incompleteness and frustration which lead disabled people to transcend their condition by artificial means ? The assumption I will develop is the following: corporeal experiences of disabled persons are mostly interpreted by transhumanists from a "universalist" conception of disability, in a way that strengthens both moral and political purpose of the transhumanist move, that is, the normative justification of human enhancement and the right to overcome human nature. Finally, I will argue that such ideological use of disabled people's life depictions within the transhumanist culture is based on two presuppositions: the first one relies on the belief that prostheses, implants and assistive technologies necessarily enhance disabled people's quality of life. The second one states that humans are necessarily disabled with regard to transhumans. Actually, both presuppositions are questionable.

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*Speaker

Recognizing agitated children as disabled in France

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Agitated children are a major concern in France. Beyond the debate on how Public Education should treat them, there has been for many years a deep scientific controversy on the origin of agitation. Defenders of a neurological perspective have developed treatments and procedures around the category of ADHD (attention deficit hyperactivity disorder). Many French health professionals are however not convinced by the scientific basis of this category and tend to see hyperactivity as a symptom and not as a diagnostic. Among them, psychanalysts are particularly opposed to this diagnostic and propose to analyze agitated children with other approaches, using psychotherapy rather than drugs. Another debate about these children concerns the boundary between social and medical problems. Many of these children live indeed in poor social conditions, which are often invoked to explain their agitation. When and why their comportment can be seen as pathological? One of the institutions which have to answer this question is, since a law on disability in 2005, the "Departmental Houses for Disability" (MDPH in french: maisons départementales des personnes handicapées). These institutions have to treat the applications of people who claim for a recognition of a disability. Some of the agitated children are considered as disabled, even if the majority of them are not. We propose to analyze these questions through a study on the life courses of agitated children in France, which is still in progress. One part of this research, which will be specifically mobilized here, concerns two MDPH located in two different French areas. In both institutions, we have led observations, interviews and data collection. The observations have been conducted during the evaluation of the applications by multidisciplinary teams (which have to prepare the official decisions) and during meetings between physicians who work for the institution and families who claimed for a recognition of a disability for an agitated child. The interviews were led with both professionals and families. Lastly, the data collection has concerned 200 applications in each MDPH we studied. Based on this material, our communication will deal with the following questions: how, under which circumstances and with which consequences can agitation lead to disability? Finally, using some supplementary elements of the global research, we will propose a reflection on the consequences of the recognition of a disability on the life courses (in medical, educational, family and administrative fields) of these children.

Keywords: children, life course, disability policy, agitation, school

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[*]Speaker

Living together in opposition to norms and values of Swedish politics and everyday life - adults with ID living with their parents

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In Sweden, the majority of people with intellectual disabilities lives in their own homes with access to service and support. The strong focus on independence in Swedish disability politics includes leaving the parental home when school is finished. Living of one's own is considered a sign of adultness in Swedish society.

In this study, however, adults with intellectual disabilities who live with their parents in Sweden are studied. These families belong to a minority group and deviate from the norms of how family life with grown up children should look like.

An overarching theme of the study is how everyday life is organized in these families and what the motives are for living together as adults.

Data

The study is based on qualitative interviews with

1) parents who have adult children with intellectual disabilities living at home and

2) adults with intellectual disabilities living with their parents

Age, as a social practice and structure, is used as a theoretical perspective. This includes age as proper behavior for certain age categories, how changing ages bring new demands and what biological aging means both to parents and adult children.

Results

The preliminary results show

1) the difficulties for people with ID to be considered adults partly because of staying with their parents

2) how the parents also violate norms of age-appropriate behavior when practical parenting continues to resemble parenting of young children such as being forced to keep appointments, to support participation in activities, and difficulties in finding "time of their own"

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*Speaker

3) how aging and growing old may change the division of labor and the relations within the families

A gender equality analysis of living conditions and participation opportunities for persons with disabilities

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The Swedish Agency for Participation has carried out a gender analysis. The aim has been to do in-depth analyses and identify gender differences concerning living conditions, participation opportunities for persons with disabilities and their access to various kinds of support from the authorities.
The study is a government assignment based on Swedish national statistics, research and investigations. It focusses on the area of education, labour market, political influence and health, in accordance with the goals of the gender equality policy of the present government.

The analysis has identified two general patterns within the areas studied: inequality in living conditions between persons with disabilities and the general population and gender inequality within the part of the population having disabilities.

Persons with disability are disadvantaged compared to the general population: they have worse living conditions, fewer opportunities to participate in society, a lower level of education and a lower rate of employment than the general population.

Girls/women with disabilities are disadvantaged compared to boys/men with disabilities. This inequality is apparent in relation to political influence, health, and in particular to the labour market. It is only within education that the girls/women have a certain advantage. But in spite of a higher level of education, women with disabilities still have a lower rate of employment than men with disabilities.
The patterns of inequality will be discussed as a result of structural or organizational flaws rather than searching for answers on an individual level. An intersectional perspective will be used as gender and disability cannot exclusively explain gender inequality as for example age, social class and level of education also have an impact on gender inequality.

Keywords: Gender, equality, intersectionality, living conditions, participation opportunities, disabilities

*Speaker

Peer counsellors' resistance to ability-centrism : a way for body emancipation

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Main disability movements focus their political views on disability both in accessibility and human rights terms. Their main goal is social change. This is the reason why the body is almost forgotten but not always. An ethnographic survey of French peer counselling (since 2010 : direct observations, focus groups, interviews, collected records, peer counsellors' writings; a variety of areas and practices have been investigated) has revealed a specific approach on body engagement in ordinary life. This approach can be analysed in terms of body practices, disability compensation and body socialisation. Thus sociological analysis enables to forward an overarching concept: the ability-centrism.

Peer counsellors' approach concerning the body lead them to design novel body practices, based on experiential knowledge. This predominance of practical over academic knowledge enables to outline original ethics of body innovation.

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[*]Speaker

Complexity and Continuity-identity constructions of persons with intellectual disabilities

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[2] Department of Social Anthropology – SE-10691, Stockholm, Sweden

The aim of the presentation is to contribute to a new theoretical understanding of the construction of self-identities of persons with intellectual disability. The analysis draws both on a review of the literature in the field and on close readings of four life stories of young adults with personal experience of intellectual disability. In the review three strands of knowledge were identified: 1) sociological studies of stable, other-defined, social identities; 2) psychological studies of stable, self-defined identities, and 3) discursive studies of dynamic self- and other-defined identities. The analysis of the literature showed that the third strand has contributed significantly to the theory of identity construction by introducing the idea of complexity and flow into our understanding of self-identities of persons with intellectual disabilities. A second conclusion is that next to nothing is said about how the studied persons could maintain a sense of self-continuity in spite of the complexity of multiple self-identities. An in-depth, interpretative analysis of expressions of self-identities in the four life histories illuminated basic aspects of both complexity and continuity. The identified narrative patterns of complexity are understood against the background of Harré's and Langenhove's theory of positioning. The concept of inner dialogue is introduced in order to make sense of the analyzed expressions of self-continuity.

Keywords: Self, identity, Intellectual disability, Positioning, Inner Dialogue

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Situational Disability - Rethinking disaster relief strategies for disabled people

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The number of disasters has been increasing all over the world. One of the most prone groups are people with disabilities. People are forgotten, cannot be evacuated or simply do not get suitable information about the ongoing events. At the same time, there is very little research on disability and disaster and the strategies for action are insufficient. (Spence 2007) The idea of two groups, people with "normal" abilities and people without, prevails and "ability" remains the leading principle. (Campbell 2009) Though the problem is that the focus on abilities does not take alternative ways into account. Someone might not have the ability to walk but this does not necessarily mean he or she cannot get from one place to another.

Based on this, the author outlines some corner points of an alternative way to rethink disability for disaster relief work. By shifting the focus from abilities to the actual possibilities for action, two important points can be made. First, disability cannot be reduced to impairments or socio-cultural disadvantages, but also includes lacking language skills and thus the inability to understand an evacuation call. This leads to the idea of situational and latent disability of everyone and overcomes the artificial divide. Second impairments do not necessarily constitute a disability. Especially impaired people often develop alternative strategies to circumvent barriers. (Saerberg 2006)

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Keywords: Disaster relief, Situational Disability, Ableism, Disaster and Disability

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*Speaker

Cripping the Future: Making Disability Count

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Over the last 8 years, we have been conducting research across a variety of sites where the presence of disability is dramatically increasing and transforming consciousness of this form of human variation. The book we are writing, entitled Disability, Personhood, and the New Normal in the 21st Century, is based on our multi-sited fieldwork. In locations as diverse as schools, medical laboratories, film festivals, homes and religious institutions, we have learned how families form new kinship imaginaries around the fact of disability; how disability publics emerge through a variety of media forms and art activism; how scientists are rethinking cognitive diversity; how schools engage with and too often fail in launching students with disabilities into the world.

Our keynote talk addresses questions of demographics and futurity that we have encountered in our work. As we have followed our subjects and our topic longitudinally across multi-sited domains, we have come to appreciate how ubiquitous disability is as a social fact in contemporary North America. The number of disabled citizens, currently estimated at almost 20% of the US population, is predicted to increase significantly over the next decade, both as an expanding portion of the population and a growing absolute number. Given the inevitable increase in disability across the life cycle, we predict that what some disability scholars/activists call "accessible futures" will remain under constant negotiation in an increasingly neo-liberal era where public expenditures are constantly at risk. At the same time, the initiatives of people with disabilities and their supporters are changing the face of both public and private culture, and most importantly, the shape of future imaginaries in which disability is understood as a central aspect of the human condition.

*Speaker

The UN Washington Group on Disability Statistics Secretariat: A New Resource for Research and Practice

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In this presentation, we provide an overview of the new UN Washington Group on Disability Statistics Secretariat, with particular attention to how this new organizing body is of relevance to researchers in Disability Studies, global health and international development.

Over the past 13 years, the UN Washington Group on Disability Statistics has played a major role in generating a methodology that allows countries, UN agencies and NGOs to collect comparable data on persons with disability in development settings. With active participation by national statistics offices, disability advocacy organisations and UN Departments, the Washington Group's work will be a cornerstone of in the collection and disaggregation of disability data in the upcoming SDGs.

Despite its central role in global disability activities, the Washington Group throughout its history has been largely organized by participating members. With growing expectations around the contributions that the Washington Group can make to the implementation, monitoring and evaluation of the SDGs and the links between the Washington Group and other methodologies under development through the UN system, the need for a more systematic approach to the on-going development, implementation and dissemination of Washington Group methodologies and information has become a priority.

In response, the Australian Department of Trade and Finance (DFAT) working with Dr Jennifer Madans, Mitchell Loeb and Dr Daniel Mont, who have spearheaded the Washington Group work, has just established a 'Washington Group' Secretariat at the Leonard Cheshire Disability and Inclusive Development Centre, University College London under the direction of Professor Nora Groce. Over the coming four years, this Secretariat is intended to provide support for training, research and dissemination for experts and advocates working on global disability and development issues. This presentation will provide an update on current and future work anticipated to be undertaken with particular relevance to how this links with UN efforts and the SDGs.

*Speaker

Now You See It, Now You Don't: Disability Studies in a Disciplinary World

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Disability studies is partly a sovereign field, partly one that is colonized by other disciplines. Historians, philosophers, sociologists, and anthropologists all study phenomena that are to do with disability, as do researchers and practitioners in the health sciences, the welfare professions, and education. The concept of disability is always in danger of being carved up and subsumed by other disciplinary categories, e.g. deviance, abnormality, marginalization, or special needs.

One strategic option, necessary but not sufficient, is the defense of the sovereign field through conferences, journals, courses, degree programs, and academic positions that are chiefly dedicated to disability studies. A complementary, perhaps more postcolonial strategy, relies on the opportunistic infection of disciplinary knowledge with disability studies perspectives.

This talk will discuss the second strategy in terms of disability discourse analysis, i.e. on how the concept of disability and disability as a category are produced in different knowledge contexts, and on the corresponding social and political effects. Disability is a very different conceptual animal in varying discourse habitats, and knowledge of these habitats may prove crucial to its continuing survival.

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*Speaker

Emergent solutions and challenges

Johanna Gustafsson [*] [1]

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Also based on the first results of the analysis of the analysis of the standard case studies, we are able to identified challenges such as aged issues, support programmes sustainability, "Not in Education, Employment nor in Training" – NEET, and lack of coordination between the various structures involved in the support of persons with disabilities.

To address some of these difficulties and challenges of the employment of persons with disabilities, the discussions between the different countries show the emergence and the development of new solutions to support the integration of persons with disabilities into the open labour market. Supported employment and customised jobs were notably mentioned. These approaches focus on the individual skills and takes into account opportunities for work in the direct environment of the persons involved. Both supported employment and customised jobs includes vocational training and individual tailored support. Vocational training can take place on the job site, but also outside, depending of the individual needs of the persons and the circumstances. However, their development varies greatly from one country to another.

For example, supported employment is at an early stage in France with first experimentations currently implemented. On the contrary, supported employment is more developed in the Netherlands and customised jobs in Sweden.

[*]Speaker

Barriers and facilitators to access paid jobs

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To illustrate how facilitators and barriers met by persons with disabilities in accessing paid jobs are addressed in the different countries, we analysed the data collected through the six standard case studies. Each case study was describing a person with disabilities working for a public employer. Neither, representativeness nor comprehensiveness was sought but we have tried to vary the type of impairments, the type of public employers, the level of education and the stage in working life. For each standard case study, a series of questions has been developed in order to describe what would happen to the person described, if she/he could benefit from some support, from what kind of support and from whom.

First results of this analysis show differences between countries for the following themes: involvement of persons with disabilities in the process of accessing or retaining a job, reasonable adjustments, workers with disabilities' status, employers' organisation, as well as structures (public employment service, dedicated public services, persons with disabilities' associations, etc.) involved in supporting persons with disabilities and employers.

For example, from one country to another, the way employers set an organisation to respond to their social responsibility to address issues related to the employment of persons with disabilities. For example, in Ireland and in France, figure such as disability liaison officer, was identified. The role of occupational services within or outside employers' organisation was also different from one country to another.

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Employment and Disability across Europe: Thoughts from the public sector

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[11] Institute for Labour and Family Research – Slovakia
[12] Innsbruck University – Austria
[13] Leeds University – United Kingdom
[14] University of Ljubljana – Slovenia

In Europe, the principle of non-discrimination has been integrated in national laws of most countries - following the adoption of Article 13 of the Amsterdam Treaty in 1997 and the Council Directive 2000/78/EC of 27 November 2000. However, the way this issue is taken into account in national or local policies may vary from one country to another. Regarding the participation of persons with disabilities to the open labour market, the range of policies remains very broad and substantial differences can be observed in terms of employment enablers, social services support, social security systems and environmental infrastructure. To date, little research has focused on this issue within the public sector. Even if at the European level, the term "public sector" or even the term "public employment" refer both to various realities for historical and political raisons, focusing on this sector was an opportunity to support discussions on how European countries were dealing with issues related to the employment of persons with disabilities. We especially focused on policies and measures implemented.

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*Speaker

Two sources of data were used. First, each country's representative has written a report on her/his country's situation including: definitions of disability and of public sector as well as an overview of the current national employment policy and statistical data. Then, to illustrate the implementation of these policies, six standard case studies were developed. Data were collected for 12 countries from 2013 to 2015 and were collectively analysed during three seminars of two days.

This session will include tree presentation. The first one will present an overview of the policies implemented. The second one will explore the barriers and facilitators met by persons with disabilities to access paid jobs. And a third one will focus on emergent solutions and challenges (see attached file for details). The session will aim at discussing and completing the results of this research project.

A Design Perspective on Participation Research

Per-Olof Hedvall * 1

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The term *participation* has been used in a wide range of contexts and scientific traditions inside and outside of the disability field. This has led to a rather large number of examples regarding how to work in practice with participation, how to study it, and what factors that are important for peoples' opportunities to take part in different activities.

The word participation is often used without a clear definition. Researchers have been trying to come up with and establish a definition that can be used throughout the whole of the disability field, but there still isn't a single definition that is used across disciplines and traditions. Instead of trying to pinpoint a single definition of the term, the purpose of this presentation is to give an overview of how participation is conceptualized and used in different fields. The presentation is based on an ongoing survey commissioned by the Swedish Agency for Participation. The survey takes its outset in the themes that are brought forward in the Agency's directives from the Swedish Government: Participation, Accessibility, Universal Design, Welfare technology (V́alf́ardsteknologi), Environment, Living Conditions, and Rights for people with disabilities. These all focus on different conditions and prerequisites for participation.

The presentation is based on preliminary results from the survey. To narrow the scope somewhat, the presentation will be presented from a design science perspective, with an emphasis on design factors and design thinking. This entails describing the conditions for participation as interwoven in the interplay between humans and artefacts. By viewing the survey's results from a design perspective, supporting human and artefactual factors will be related to each other while maintaining peoples' needs, wishes and dreams as the main driver behind the activities at hand.

Keywords: Participation, people with disabilities, accessibility, universal design, welfare technology

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*Speaker

Knowing, being or doing? Perceptions among human service professionals about quality in day-to-day encounters with people with intellectual disabilities.

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The presentation rests on the assumption that one feature of quality in service provision in human service organizations is knowing how to demonstrate ethical awareness through professional judgements and decide and act within a framework of professional accountability. But what does it mean to decide, act and behave in a professional manner toward people with ID? The presentation reports on perceptions of quality in professional encounters with people with ID among human services professionals in Sweden. To be able to differentiate between different experiences and opinions, we draw on three different institutional contexts: schools, social services and healthcare. The result presented draw on data gathered from a total of 421 human service professionals who answered an open-ended question in a web-based questionnaire. In all, 872 written excerpts were included for analysis. The results reveals four core categories of quality in professional encounters with people with ID; (1) personal attributes, (2) pertinent knowledge, (3) professional action, and (4) ideological awareness. To conclude, we argue that our findings add to the growing body of literature concerning a pluralistic understanding of the characteristics of professionals' conditions, prerequisites and perceptions within human service organizations.

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Communicating and hand(ling) technologies. Everyday life in educational settings where pupils with cochlear implants are mainstreamed

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In this study, we take an ethnographical approach to the way that learning and instruction is organized in Swedish primary school classrooms for deaf pupils who wear a surgically implanted cochlear hearing aid. The study addresses questions related to communication, language use, and identity positions in the everyday lives of these children in school settings. In mainstream classrooms where these children are members, different types of technologies are commonly used. The study takes sociocultural (Wertsch, 1998; Vygotsky, 1978) and language ideology (Irvine 1989; Irvine and Gal 2000; Kroskrity 2010) perspectives as points of departure and specifically examines the role of a range of technologies that are deployed in these settings, their application, how pupils react to them, and how the technologies shape classroom interaction. The ethnographic data includes fieldwork notes, video-recordings and conversations with professionals in two mainstream classrooms in Sweden. The ethnographically framed analysis includes a modified version of a Conversation Analysis transcription that has enabled the representation of mundane interaction complexities, including visual elements. Our findings show that the use of different technologies significantly shape deaf pupils' opportunities to access and participate in everyday classroom life. The hegemonic position wielded by adults with regard to technology usage also has specific implications for deaf pupils with cochlear implants. The results also indicate that language ideologies play out in specific ways in the highly technified mainstream classroom environments. Oral communication tends to be privileged while visually-oriented communication is marginalized. At an overarching level, the findings indicate that pupils with cochlear implants have a peripheral identity position in mainstream classrooms. The findings have major relevance in that they contribute to an important gap in the literature on the mainstream situation of deaf pupils with cochlear implantation.

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"And so it was – later on, we found each other directly" – a narrative analysis of five young men's experience of participation by utilizing personal assistance.

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According to Swedish disability policy, all people, regardless of their functional abilities, should have the same opportunities to participate in society and take part of human rights (LSS, 1994). This study is part of a larger research project with the overall aim to explore children and young peoples' experience of living with personal assistance and participating in meetings with social workers responsible for giving them access to personal assistance. A previous GT study (Hultman, Forinder, Pergert, 2015) reveled that adolescents' main concern was to achieve normality which is about doing rather than being normal. They tried to resolve this by utilizing personal assistance – assisted normality. This oral presentation is based on three individual interviews included in the previous study and two additional interviews. The participants are young men between 15- 19 years who to varying degrees use personal assistance in their everyday life due to different types of physical impairments. The aim was to explore the young men's experiences of participation by utilizing personal assistance. Their stories are analyzed according to narrative analysis (Crossley, 2000). The young men tell us how their different experiences of participation are affected by both internal and external factors. Their narratives provide insight into how the interplay between themselves, their personal assistants and the surrounding environment contribute to their experiences of participation. The results show that experiences of participation are affected by their own and others conception about normality and disability, as well as accessibility to activities and contexts in which one wants to participate, as well as the co-operation and relation between the assistance user and the personal assistant.

[*]Speaker

The experiences of societal participation of people with disabilities: An interview-study among people with disabilities in Finland

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Participation in different areas of life, such as the labour market or leisure activities, is important for everyone. The experiences of societal participation for people with disabilities may however be influenced by different kinds of barriers limiting the participation, as well as enabling factors, which enhance participation. Therefore societal participation is a corner stone for disability policies in Finland, as well as internationally. The aim of this study is to shed light on how people with disabilities in Finland experience their own societal participation and to examine what kind of barriers and facilitators they highlight. The study consists of 13 individual qualitative interviews among working-age people with different kinds of disabilities. The general aim is divided into the following research questions; what kind of meaning do people with disabilities themselves give to societal participation, and how do they experience their own participation in society? What kind of facilitators do they identify for their societal participation and what do they consider as possible challenges or barriers? And finally, what do they see as to be needed in order to favour participation of people with disabilities, both regarding themselves and people with disabilities in general? The findings show that the persons interviewed see societal participation primarily in terms of a right to equality i.e. to be able to do the same things as everyone else. Most of them also consider themselves as quite involved in society, and also see a positive trend concerning the societal participation of people with disabilities in general. Different kinds of disability services, assistive technology and legislation were some of the facilitators highlighted, while for example inaccessibility and negative attitudes were seen as barriers to societal participation. Many of the persons interviewed called for increased accessibility and improvement in attitudes in society, as well as more flexibility and individual solutions concerning disability services.

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Fulfilling the Intentions of CRPD Article 29: Involving People with Disabilities in Public Affairs

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The presentation will begin by considering the framework for political participation presented in Article 29 of the CRPD (participation in political and public life). It will offer a comparative analysis of how State Parties have been reporting on Article 29 relevant to five key themes: who can vote; accessibility of elections; encouragement/ability to stand for election and hold public office; membership in organizations and associations; and involvement in public affairs. Data from all state CRPD reports available in English (as of 1 January 2016) will be considered in the analysis and both quantitative and qualitative findings will be presented. The second portion of the presentation will focus on active engagement in political decision-making (points two and five above) using case studies to highlight examples of approaches to inclusive involvement in public affairs. Personal narratives from people with disabilities involved in influencing political decisions (as elected representatives, independent activists, and members of government advisory committees) in a number of different countries will be used. While topics of physical accommodation will be covered, special attention will be paid to the inclusion of people with intellectual disabilities in the UK and Ireland (based on the preliminary findings from an ongoing qualitative study).

Keywords: CRPD, Political Participation, Civic Engagement, Public Affairs, Citizenship, Inclusion, Human Rights, International Comparative Research

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*Speaker

Human service organizations and intellectual disabilities - ORGID

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2, Lennart Sauer *

1, Jan Hjelte *

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1 Umea University (SWEDEN) – Sweden
2 University West in Trollhättan, Sweden – Sweden
3 Department of support and development at Umeå Municipality – Sweden

In this session we report results and findings from empirical studies conducted within a larger research project, situated at Umeå University, Sweden. The project is called "Between organizational interests and individuality. On policy, leadership and organization of support for people with intellectual disabilities in schools, social services and public health-care". In our session we report on three different studies (see abstracts). All presentations are based on a mixed method approach, combining quantitative and qualitative analysis from a larger web-based survey (n=421), which included both standardized questions (Likert-Scale) and open-ended questions. Hence, we report both content and frequency of responses. Our session also has comparative ambitions as respondents represent different human service organizations: schools, social services and public health-care. Our first presentation report and analyse professional experiences of difficult encounters working with people with intellectual disabilities. In our second presentations we examine how sources of job satisfaction was articulated by human service professionals and the way in which organizational context influence these experiences. Our third presentation explores perceptions of quality in professional encounters with people with intellectual disabilities in Sweden. We also draw attention to the way these perceptions may be seen as culture-specific and shaped by organizational context. In all, we believe that our results add to the discussion of challenges-administrative, organizational, and institutional-among human service professions working with people with intellectual disabilities. It also has implication on client- and user experiences of service provision in different welfare organizations, considering that norms, values and perceptions within institutional organizations are not easily changed, regardless of political rhetoric.
Participants

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Students with disabilities and their experiences of higher education- a comparative institutional analysis of equal opportunities in Sweden, The Czech Republic and the United States

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For persons with disabilities a university degree may be one of few options to gain access to the labour market (Riddell et al., 2005). Yet, in most countries persons with disabilities face hardships in accessing and taking part in university studies (Vidali 2007, Fuller et al. 2009). The aim of this study is to investigate how the institutional context shapes students' experiences of equal opportunities in higher education. Students (n=45) from five different universities in Sweden, the Czech Republic, and the USA were interviewed.

An institutional analysis following Scotts (2013) theoretical framework emphasizes how the regulative- , the normative-, and the cognitive elements of the university as an institution shape student's experiences. The laws that support equal opportunities in higher education are important regulative conditions. The process of providing students with support in their studies form the normative element and student's experiences of interaction with academic staff express the cognitive elements.

Overall, the study has shown that students' possibilities for equal participation are shaped by the institutional context that is based on medical diagnosis and compensation for an inaccessible education. Regulative elements are moving in the same direction. All three countries have political intentions to increase participation in higher education for disabled persons.

Also, the cognitive elements; students' experiences and strategies are alike since all students' experience that the relationship with the teacher is decisive for their chances of succeeding in their studies.

The normative elements, however, influence the actual possibility of equal participation. Students experience that the procedure to apply for support is based on a medical model demanding students to present a medical diagnoses in order to be eligible for support. We conclude that universities need to change their practice to apply equal opportunities for all students.

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*Speaker

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Changes in services - changes in attitudes?

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The dismantling of institutions for people with intellectual disabilities in Norway took place through a reform in the 1990's. The ideals of the reform were that people with intellectual disabilities should live in their own apartments, take part in work life or other daytime activities and lead an active life in their leisure time. The support needed should be given on an individual basis. Today, these ideals seem to have been left. Living arrangements are more institutionalized, few are in paid work and many take part in segregated leisure time activities. The driving forces behind this rather negative development could for instance be: organizational changes in the municipalities, less media attention, less power among professionals and advocates, other groups in focus. In addition, it is possible to ask whether the new situation has to do with attitudes towards people with intellectual disabilities.

Based on studies of the living conditions for people with intellectual disabilities in the period from 1992 to 2010, and a qualitative study about the experiences of seven young individuals with intellectual disabilities, this paper will discuss possible connections between societal attitudes people with intellectual disabilities and how the services are constructed. The qualitative study is analyzed with a hermeneutic approach in order to catch the first person perspective of the participants. Results from this study indicate that even if these young individuals want to live what they call ordinary lives, they have experienced barriers because of negative attitudes from both individuals and organisations.

Keywords: intellectual disability, living conditions, attitudes

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[*]Speaker

Artistry and Disability – Doing Art for Real? Affordances at a Daily Activity Centre with an artistic profile

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People with neuropsychiatric disabilities are a growing group that sometimes have their work-placement in Daily Activity Centres. These new groups of young people have grown up with a political agenda that emphasizes participation and independence. Thus, they have different expectations on their future than earlier generations. Taking our point of departure in critical disability studies this study explores affordances of a Daily Activity Centre with an artistic profile according to its' participants; people with neuropsychiatric disabilities. The analysis reveals that this Centre, 'Studio X', has two fundamental meanings to the participants; it is a place to create art and a 'safe haven'. These two key meanings can be related to two different logics. The logic of art focuses on the cultural and creative dimensions of Studio X. The therapeutic logic builds on the organisational belonging of the Centre and a rationale of welfare state responsibility. The participants position themselves as artists contributing to society, not as social clients. Moreover, the therapeutic logic at Studio X can be described as a 'celebration of difference' and not as a 'normalisation project'. This institutional setting does not seem to be governed by a desire to 'normalise' or 'alter' their participants, but rather to see them as competent members of an artistic community. However, with organisational changes there has been a shift towards the therapeutic logic and participants experience less influence, participation and self-determination. By applying an 'ableism lens' onto this shift, participants at Studio X, are positioned as less able to take responsibility. Their voices are not as valued, and they are put in a more subordinated position than before. Thus, when the therapeutic logic is more pronounced and the logic of art in the background, there is a risk of top-down perspective that reproduces the norms of ableism.

Keywords: Neuropsychiatric disabilities, art, Daily Activity Centre, disability studies, ableism

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Individual concepts and experiences of adulthood of people with intellectual disabilities in the context of inclusion/exclusion, participation and human rights

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In our presentation we concentrate on the phenomenon of being adult with intellectual disability in the context of participation, inclusion/exclusion and meaning making. We want to show the results of the research which aimed to reconstruct the experiences of the participants as adults and focused on the meanings they ascribe to the concept of adulthood: we wanted to see the ways in which they understand and define their individual biographical experiences connected with adulthood and disability.

The presented analyses refer to the selected group of adults with intellectual disabilities, participants of Polish workshops of occupational therapy and community self-help homes, functioning within contemporary Polish social support system for people with disabilities. It includes many institutions and organizations which conduct various activities aiming for social and occupational rehabilitation, social integration, countering social exclusion of these people and improving their life quality.

The research was realized applying qualitative model of enquiry: we used individual and group ethnographic and biographic interviews with 26 participants – women and men with intellectual disabilities, aged 24 – 53. Participants narrations revealed the meanings ascribed to adulthood showing actual and missing fields of experiences/activities like: family life, vocational activities, health, leisure time and joy, interpersonal relationships, being a couple, love, marriage. Their concept of adulthood/ being adult appears however the matter of some individual needs, desires and expectations/or even imagination rather than real/ actual life experience. This makes us to suggest that integrating, inclusion, participation and normalization processes seem to fail as far as social supporting of people with intellectual disabilities in adulthood is concerned.

In the context of our research, social integration and inclusion appear not only an important ideas and human rights, but they significantly influence the quality of life of adults with intellectual disabilities, providing a better direct and adjust social support in the experience of adulthood, adequately/or not to their needs, expectations and individual abilities, exposing so-

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*Speaker

cial background they live in.

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Experience and forms of uses of disability compensation devices in French universities

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This work is part of a research program on the ethical issues related to the implementation of public policies towards a category of users: "students with disabilities". From the perspective of international comparison (France-Québec), the objective is to focus on the treatment of particular type of beneficiaries, qualified by the universities actors, of "emerging" and / or with an "invisible" disability.

This communication is focused on the reception of concrete mechanisms (Foucault, 1994) by the concerned students. While many works (Bertrand et.al, 2014; Blanc, 2009), are available on the uses of the french "Recognition of Quality of Disabled Worker (RQTH)", few relate to those of the status of "disabled student." This public class action is, indeed, both recent and quantitatively restricted.

Using data from a national survey conducted by questionnaire to current and former students with disabilities (n = 710) in French universities, we propose to examine the use of these devices in three steps:

- first the existing "modalities" of access and "forms" of uses will be presented: when, with whom and how students become "students with disabilities" and how this approach is taking part of their life and study course?

- Then, we will analyze the experiences of accomodation in order to measure the multiple uses of existing devices and to identify possible resistance to them.

- Finally, we will wonder the evaluation of devices. It appears that the "users" are "satisfied" with the accomodations offered: 92% of them feel they corresponded "strongly" or "somewhat well" to their needs. How do these academic devices manage to compensate disabilities? What limitations may still exist? What is going on with "invisible" and / or "emerging" disabilities?

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"emerging" or "invisibility" of disability notions will be discussed during a seminar in January 2016. These concepts includes groups of students whose proportion is increasing and ranked in "language and speech disorders " and "mental disorders" catégories.

People with support from the Swedish Disability Act (1993:387) – included or in charge?

Susanne Larsson [*][†] [1]

[1] Ersta Sköndal Högskola – Sweden

A review of Swedish research efforts on the Swedish Disability Act (1993:387) and how it affects supported persons power over their own lives.
Ingress

Sweden represents a well-developed welfare state and The Swedish Disability Act (1993:387) was implemented in the early 1990's. The costly ambitions formulated in this Act have partly been legitimatized by arguments linked to empowerment.

SDA aims to ensure that people with disabilities can lead their lives under the same conditions as others. It is claimed that supported persons should, as far as possible, be in charge of how support efforts is decided, planned and executed. Put differently, SDA should empower its target group.

This study aims to review Swedish research on SDA during the last fifteen years, focusing its empowerment functions. To what extent are persons with disabilities in charge of support efforts, and how is this described and discussed in research?

Type of data

The review includes thesis, journal articles, books, research reports and government reports on SDA during 2000-2015, presented in Swedish or English. Texts are selected, read, compiled and analyzed from an empowerment perspective, based on the target group's possibilities to take part and decide about support efforts.

Result and analyze

Results from the study embraces 1) the quantity of research conducted on SDA in Sweden, 2) how SDA is described and analyzed within existing research, 3) how SDA is understood in relation to empowerment, and 4) how empowerment is executed within the context of efforts based on SDA.

Tentatively, SDA is well studied in Sweden, primarily within a disability research context. In

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this, empowerment is often mentioned, but seldom analyzed/theorized. In this study, learnings as well as lack of knowledge are identified, and more research focusing SDA in relation to empowerment, theoretical as well as empirical, is called for.

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Participation in physical activities for children with physical disabilities: feasibility and effectiveness of physical activity referrals

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Background: Children with physical disabilities are at risk to develop cardiometabolic diseases because of inactivity. An active lifestyle with increased habitual physical activity and reduced sedentary behaviour is recommended. Physical Activity Referral (PAR) is an effective intervention to promote a lifestyle change in adults. There is a lack of knowledge about PAR in children with disabilities.

Aim: To evaluate the feasibility and effectiveness of PAR for children with physical disabilities

Method: 11 children with CP and 3 children with other physical disabilities, aged 7-12 years, and their parents participated in PAR, with assessments at baseline, 8 and 11 months. Sociodemographic, clinical and physical activity questionnaires were conducted at baseline; GMFM-66, physical activity and heart rate monitors and time use diaries were used at baseline and at 8 months. Motivational Interviewing and the Canadian Occupational Performance Measure (COPM) led to a written agreement between each child, its parents and the physiotherapist by using Goal Attainment Scaling (GAS). At 8 and at 11 months COPM and GAS were evaluated and PAR-evaluation, physical activity and costs & time spent questionnaires were completed. At 11 months feedback was given of measured physical activity levels and GMFM-66 scores.

Result: Each child participated in 1-3 self-selected physical activities with support of the physiotherapist. PAR involved both everyday physical activities as biking to school and organised physical activities as wheelchair hockey due to individual preferences, opportunities and facilities. Measuring physical activity levels was motivating, COPM, GAS and GMFM-66 scores increased and several children made new friends.

Conclusion: PAR seems to be feasible and effective. PAR promotes an active lifestyle through increased participation, motivation and engagement in physical activities and increased social participation. Further research is needed, preferably in a RCT including health economic analysis.

*Speaker

Inclusive Music and the Capabilities Framework: contextualising the experiences of inclusive music in the lives of children and young people with disabilities

Susan Levy * [1]

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This study is situated within the field of inclusive arts and disability. Findings will be presented on a project that explored the impact on the lives of children and young people with disabilities of participating in inclusive music classes in a community arts organisation in Glasgow, Scotland. Qualitative data were collected for the study through the observation of classes and performances, talking to the participants, a parent questionnaire and focus group with the music tutors. The findings are interpreted through the capabilities approach of Sen (2001) and Nussbaum (2006), and personalisation. The study highlights that involvement in inclusive music classes impacts on the confidence, sense of achievement and overall wellbeing of the participants. The development of transferable life skills appears to be contesting and layering the identities of the children and young people, helping them to see themselves as musicians and motivating them to achieve in other areas of their lives. The inclusive music classes are creating safe and supportive spaces and opportunities for the young participants to lead a life of their own choosing. This study contributes to the empirical work on the 'transformative potential' (Atkinson and Robson, 2012) of participation in the creative arts, specifically highlighting how this can be achieved when the concept of personalisation is applied in practice from a social justice perspective.

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*Speaker

Negotiating consent throughout the research process. Participation on the participant's terms.

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Abstract

The purpose of this presentation is to discuss negotiation of consent and participation in a research project on the meaning of music for First Nations children diagnosed with Autism Spectrum Disorder, ASD, in British Columbia, Canada, and to obtain comments and feedback from the scientific community.

Background

Informed consent is a strong ethical principal in any research project. However, when the participant has a disability, it can be difficult for the researcher to know if the participant actually understands what participation in the project entails. In my project, I have negotiated consent and participation with the participating five children throughout the research process. The participants are vulnerable, not only because of their disability, but also due to marginalization in a society where colonial residue is ever-present in daily life.

Methodology

This is an ethnographic study inspired by Indigenous Research Methodologies. Interviews were conducted in 2013 and follow-up interviews, observations, video-filmed observations and field notes in 2014. Interviews were transcribed and analyzed from five research questions and the results made in to mind-maps from every individual interview. These mind-maps were used as a mutual focal point in the follow-up interviews to disseminate results and ensure correct interpretation. Relevant sequences from the film material were analyzed in the software ELAN and the hand-written field notes typed on the computer.

Results

The material illustrates how consent and participation is negotiated in multiple ways with the participants throughout the research process. This was done by written consent, by asking about participation during the interview or observation, by using the mind-map, and by picking up on signals from the participant. By ensuring their informed decisions to continue their participation, power imbalance was addressed and their rights were respected, which is particularly

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*Speaker

important when conducting research within Indigenous contexts.

Keywords: First Nations, Autism, Consent, Power, Rights

Monitoring UNCRPD in a national perspective

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A central part of monitoring human rights, the UNCRPD in particular, is the follow up and measuring of the content of the convention. The establishment of a system for follow up requires measurements at different societal levels such as the national, regional, local and individual. It furthermore requires an intersectoral approach, i.e. accessibility in different policy areas such as transport, education or the labour market. Is also fundamental to have a perspective of the relation of conditions and effects in which conditions are the process that aim to increase equality and effects the outcome in terms of equality. A key challenge when following up and measuring the content of the UNCRPD is to apply intersectional perspectives in order to be able to gain an understanding on the complexity of inequalities and structural discrimination.

The Swedish Agency for Participation has been assigned to develop a system for follow up of Swedish Disability policy. Thus it is not a system for monitoring the UNCRPD, it is a vital part of providing a basis for the State responsibility to monitor in accordance to the UNCRPD. The current system includes measures from a multitude of sources at different levels such as:

- National statistics on individuals that measures outcome in terms of equality

- Surveys to governmental agencies and municipalities that measures processes for participation

- Individual panel consisting of persons with disabilities measuring perceived obstacles to participation

- Qualitative studies

- Data from other sources regarding i.e. accessibility measures
Given the scope of the UNCRPD and demands of intersectoral and intersectional approaches the follow up system is under continual development.

Keywords: Human rights, UNCRPD, follow up, monitoring, disability policy, equality

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*Speaker

Advocacy on behalf of those who cannot instruct: Perspectives of English Non-instructed Advocates

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Advocacy as a tool for social change is particularly established across Europe in contexts of mental illness and intellectual disability. The development of advocacy organisations such as those in England and Wales, the work of Advocacy France, and the Swedish Personal Ombudsman system, (with related models adopted in Norway, Finland and the Czech Republic), originated in a strong critique of the social control function of psychiatry, and demonstrate commitment to state-operated advocacy. However, unlike in some countries, including Sweden and France, where advocacy roles are fundamentally associated with receiving commissions from, and representing the wishes of the person being advocated for, advocates in England and Wales may work on a non-instructed basis, where an individual is "unable to give a clear indication of their views or wishes in a specific situation' (Henderson, 2007).

This paper draws upon thematically analysed data comprising in-depth interviews and focus group discussion (a total of 13.7 hours of recorded data) with twelve English advocates, examining their construction of non-instructed advocacy. Findings suggest that advocates are committed to non-instructed practice as a way of representing the most vulnerable members of society, and are emotionally invested in their work, engaging in emotional labour as conceptualised by Hochschild (2003). There is evidence however, that they view non-instructed practice as more challenging than instructed advocacy and identify it as undervalued and under-resourced. Particular challenges are associated with the best interest decision-making framework of the Mental Capacity Act 2005, which creates a statutory right to advocacy in certain circumstances but may result in a decision being made contrary to the wishes of the client. Implications for non-instructed advocacy as a tool for protecting the rights of the most vulnerable in society are considered in the light of these findings.

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An empty arena – on attitudes to and experiences of sexuality education among special school and habilitation service staff in Sweden

Jack Lukkerz [*][1]

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Young people with intellectual disabilities (ID) grow up in environments strongly influenced by parents' and staff's values on gender, sexuality and disability. This may create barriers in promoting the youth's knowledge about their bodies and possibilities to sexual expression and sexual health. In this study, Swedish special needs school teachers and habilitation staff participated in nine focus group interviews, and shared their views and experiences of working with sexuality education. The data were analysed using the theory of Social Representations in order to capture the staff's everyday knowledge on sexuality and sexuality education. The data points to attitudes expressed both explicitly and implicitly, found on an individual as well as a structural level. E.g. sexuality among people with ID is largely seen as problematic and risky while pleasurable aspects are made invisible. Young people with ID are expected to take responsibility for possible risks in their surroundings while their sexuality is seen as different from others'. Stereotypes about gender and sexual expression are significant. Non-heterosexual persons with ID are present, although seen as a challenge to the daily work. Parents of the youth are seen as obstacles in the implementation of sexuality education. The professionals also express a lack of education and practice regarding sexuality education. Furthermore, they emphasize the need for leader support in order to establish professional self-esteem, as well as to allow for creativity and independence in the implementation of sexuality education. A norm critical (e.g. awareness of own values regarding gender, sexuality and disability, as well as a critical approach to current perceptions among colleagues or in society in general), more equivalent sexuality education that includes both risk reduction and positive and enjoyable aspects of sexuality, and a clear framework of the subject of sexuality education are recommended.

Keywords: Sexuality, intellectual disabilities, sexuality education, special schools

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[*]Speaker

Perspectives on difference and stigma: researching the lives of people with albinism in Malawi

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Albinism is a genetically inherited condition which causes a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. Over the past few years there has been an alarming rise in the number of cases of violence against people with albinism including the trafficking in persons and the sale of children, infanticide and abandonment of children killing and attacks with a view to using their body parts for ritual purposes. This presentation will share some of the findings from a research project funded by the British Academy to investigate how a life-threatening, dehumanizing phenomenon is impacting the lives of people with albinism and their families and how we explored ways to better protect them in their homes and communities and ultimately raise awareness of their human rights.

We sought to use participatory research techniques the team designed tools (interviews, focus groups and observations) that would give equal opportunity and voice to children and young people with albinism, their families as well as teaching professionals and community workers who support these children in mainstream schools and resource centres. Despite limited resources, parents and older children interviewed showed great resiliency and agency in being able to deal with the barriers in different and courageous ways. There was strong evidence that the children and their families faced multiple prejudices and experienced insecurity in their communities and at school which led to feelings of anxiety and disablism, and more noticeably detachment from the communities. Many of these individuals felt isolated and vulnerable within their own communities.

In the final part of the paper I will discuss how we should critically engage with the politics of conducting research into difference and stigma in the global South and examine how we research similar disability issues in future research.

Keywords: Albinism, Malawi, human rights, inclusion, education

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[*]Speaker

The unexpected developments in disability sports. What does it all mean?

Anne Marcellini [*][†] [1]

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Since the 1990s, we have researched, together with a number of colleagues and students, the physical activity of persons with disabilities, focusing on different types of physical and sports practises and studying them at different levels, from the micro- to the macro-social level.

Drawing on an interactionist perspective, we initially explored how people with various impairments interacted with others within social spaces where physical and sports activities were being practised. We wanted to understand how face to face interactions could be transformed in the specific context of physical experiences with others. How did the setting in motion of the impaired body, which can lead to new ways of staging oneself, allow changes in social interactions at a micro-social level? Though the relationship between singular bodies, bodies in motion, social bonds and identities are central to our reflections, we very soon had to take into account the organizational and institutional frameworks for studying the physical activities we observed.

On the basis of practices initially mostly limited to rehabilitation prospects, or confined within peer groups inside the world of disability, a process of integration into sports associations or common sports areas was developed, which at the same time reinforced a trend of growing participation in sports. Specific sports organizations, local, national and international, have been set up at the interface between the world of disability and sports, promoting sports events that have turned into global sporting spectacles, the images of which have been more and more multiplied by the media.

This keynote speech aims to examine the meanings of the extraordinary developments, unexpected to some, that we can observe in the physical and sports practises of people with disabilities. Indeed, if history is the laboratory of the sociologist, as Norbert Elias said, we could venture that the history of sports and physical activities of people with a disability is an exceptional laboratory for the sociologist interested in researching otherness, diversity and the mechanisms that people can devise to learn how to live with others. From the shame of impairment to the pride of a relative body performance and its exhibition in sport also entails a deconstruction of the subordinate status of people with impairments.

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Risks and opportunities in new emancipatory landscapes? On young people with intellectual disabilities, Internet use and identification processes

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Although research on young peoples identity formation processes on the Internet is a growing field, there are few studies that illustrate conditions for pupils with intellectual disabilities (ID). Recent Scandinavian studies have indicated that there is a new generation of young people with ID who has developed alternative ways of relating to issues of participation and identity. It's about how they choose to present themselves and how they navigate the various social media. By presenting themselves through descriptions of their own interests and personal characteristics instead of exposing the disability so-called alternative identities can be developed, where disability is not necessarily put in focus. Young people with ID often have different degrees of communicative constraints, which on the one hand implicates that the value of new social arenas can be of great importance. On the other hand, the use of the Internet could also be problematic in different contexts. An on-going Swedish research project aims to investigate these processes based on the perspectives of young people with ID, school staff and parents. In a pilot study based on focus group interviews we found that professionals (teachers, n=8) expressed a concern that young people will get hurt and end up in undesirable situations (such as being cheated or abused), while parents (n=5) mainly consider the Internet as a possible future venue for the development of new and on-going social relations. This paper presentation will report preliminary findings from interviews conducted with young people in upper secondary special programme for pupils with ID (n=30). The experiences of the informants will be discussed in relation to results from the pilot study and relative to a conceptual framework of social identity, participation and emancipation.

Keywords: Intellectual disability, Internet, social participation, social media, identification processes

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*Speaker

Handle with Care: Staff Experiences of Difficulties working with People with Intellectual Disabilities

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Providing care and support to people with intellectual disabilities (ID) is in several aspects a complex and challenging assignment. It could be argued that this complexity has fundamentally to do with different organizational conditions. Analysing the specific characteristics of experienced difficulties could generate a new understanding of the organizational prerequisites of working within intellectual disability services. This presentation examines how LSS administrators (n=70) and habilitation staff (n=40) in Sweden experience difficulties working with people with ID. Drawing upon both quantitative and qualitative data generated from a larger web survey a content analysis was used. In order to complement the qualitative analyses we also used descriptive numerical analyses. The results reveals that staff experiences of difficulties in work with people with ID could be differentiated in four typological themes; (1) Structure, (2) Profession, (3) Relations and (4) Collaboration. As shown in our presentation, experience of difficult situations in human service organizations does not necessarily correspond with work dissatisfaction or unclear goals. On the contrary, we argue that it is a fundamental aspect of professionalism to handle this plurality within a specific organizational context. The different characteristics of the organizations in our study reflect two different institutional logics. While the LSS administrators mainly operates within *an administrative logic* based on a regulative framework, the habilitation staff are operating within *a therapeutic logic* based on a cognitive framework. Consequently they have their own specific norms and rule systems, which influence when and to which extent everyday situations are experience and defined as difficult.

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Disability and Inclusive Processes at School. Exploring Conceptual and Interpretative Models from the Point of View of Special Pedagogy

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It is not easy to state what disability is. In order to answer to this question referring to the twentieth century – except for some prominent personalities in the scientific context (Binet, Decroly, Montessori, Vygotskij) – it could be stated that the second half of the century marks the end of a millenary era in which the topic of disability was viewed merely in fatalistic terms. During the second part of the century, there were attempts to delineate the concept of disability through different conceptual and interpretative models, all of them being very interesting from a scientific point of view (Disability Studies, Disability Creation Process, OMS' Classifications, Capability Approach).

The reflection about human experience reveals a certain divergence between the condition of the individual, centred in their own biographic reality, and the effects of the social construction that determine different life conditions, which result to be standardised by concepts and categories. Depending on the incisiveness of such effects, the understanding and peruse of the disabled person's existential condition become involved.

In facts, if we consider the classificatory models singularly, they do not seem to be sufficient to show and to describe the sense and the meaning that disability has in relationship to the peculiarity of existential life conditions. Combining them into a single one is not enough. Our analysis argues and shows in what sense they don't completely satisfy the perspective into which the Italian Special Pedagogy conceives disability and inclusive processes at school, especially from the point of view of teachers' didactical work.

The way in which each individual conceives themselves and understands their own condition plays a determinant role in the definition of their health and life conditions, but this is a question that does not find a full answer in any of the interpretative models of disability. In order to be understood in the most authentic way, disability has to be conceived as an existential condition that needs to take into account the identity of the disabled person referring to their personal real life dimension, rather than to the interpretative models only.

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Schooling pupils with disabilities in France and Cameroon: a comparative analysis

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The right to education and academic success of all are the concerns of all time regardless of the contexts (UNESCO, 2008). Unfortunately, despite the solemn affirmations and commitments to education for all and inclusive education, the question of the effectiveness of including all-out pupils with disabilities remains a relatively unexplored topic. Inclusive education implies a paradigm shift in which the conditions for success are based on the ability of the school to adapt to the diversity of the public it hosts (Plaisance, Belmont, Vérillon et al., 2007; Dyson, Millward et al., 1999).
Some researchers (Armstrong, 2001; Ainscow, 2003) showed that if educational policies are formulated around the differences of pupils, they favor inclusion; such policies in addition to their voluntary nature, should provide mechanisms to the effective management of pupils at school.

Therefore, one can question the quality of systems set up in France and Cameroon to host and assist students with disabilities.
From the multidimensional evaluation model of the quality of school systems (Tremblay, 2012), quantitative data were collected by questionnaires from 133 teachers in France and Cameroon. The ANOVA test is used for the comparison of means between the two countries. The results show points of similarities and significant differences that will be presented and discussed.

Keywords: inclusion, disability, education policy, international comparison, France, Cameroon

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The inclusive school in Portugal: the perspective of teachers, families and key actors

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Since the World Conference on Special Needs Education, organized by the Government of Spain in cooperation with UNESCO in 1994, the paradigm of "Education for All" has been consolidated: to provide education for children and youth with disabilities in the regular education system. In the last years, Portugal implemented interesting policies to ensure that all children with disabilities, including those with autism, have access to a quality education in the mainstream public education system. Reference schools for autism and implemented structured units of education based on the TEACCH method were created within the regular system. Nevertheless, the children continue to be part of the regular class.

The presentation is based on new data exploration of a recent quantitative study concerning the impact of public schools on the quality of life of children with autism their families (Nogueira et al. 2014) complemented with data obtained by qualitative methods. A survey was administered to a sample of 300 households with children/youth with autism. In addition, information was also obtained by interviews and focus group to professionals, teachers and other stakeholders. Quantitative data were analyzed using SPSS and qualitative data was studied through content analysis.

The main domains of the analysis are: i) the access to the public education system; ii) families satisfaction about the inclusion process; ii) the resources and players; iii) the training of educators and the adequacy of the methods; iv) family support; and v) the impact of public school in the family and child with autism syndrome disorder.

Keywords: inclusive school, human rights, participation, public education system

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A Conceptual Model of Factors Leading to the Inclusion of People with Neurodevelopmental Disorders in the Digital World

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The development of Internet has revolutionized the way humans interact, online as well as offline. In the words of Tim Berners-Lee, "the power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect." However, people with neurodevelopmental disorders (i.e. intellectual disability or autism spectrum disorder) share sensorimotor, cognitive or social impairments that limit accessibility to the WWW and their use of Internet, thereby reducing their potential for social participation in this virtual community. Our study aims to build a model of factors that could facilitate inclusion in the digital world for people with ID or ASD.

A review of the literature was performed to identify factors associated with digital exclusion of people with neurodevelopmental disorders.

This analysis led to the creation of a digital accessibility pyramid, comprising five levels: 1- access to digital devices, 2- sensorimotor skills, 3- cognitive skills, 4- technical skills, 5- social skills. Progression in the pyramid is based on the premise that to ensure optimal use of the information and communication technologies, people must develop the necessary skills or receive the necessary support from their environment to attain each level from the bottom up. Ethical and psychosocial issues permeate each of these levels, leading to the addition of a transversal dimension to the model.

By addressing these issues, we could ensure the digital social participation not only of people with ID/ASD but other disabilities as well.

Keywords: Internet, digital divide, accessibility, social participation, intellectual disability, autism spectrum disorder

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*Speaker

Risks and Benefits of Internet Use by People with Neurodevelopmental Disorders

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Electronic social media facilitate the development of relationships, which could lead to greater social inclusion for people with neurodevelopmental disorders [i.e. intellectual disability (ID) or autism spectrum disorder (ASD)]. While there is a dearth of research on Internet use by people with ID or ASD, families, educators and support workers have voiced concerns about online safety.

Our study attempts to produce an overview of experiences with Internet from young adults with a diagnosis of ID or ASD. Sample: Preliminary results are available on eight subjects: five with ID (3 males, 2 females), and three with ASD (2 males, 3 females) with a mean age of 25 years. Methodology: A sociodemographic and Internet use questionnaire was administered with the help of the participants' support worker, followed by an in-depth interview with one of the researchers.

All participants used Internet for consuming content (e.g. watching videos, listening to music, checking sports results, pornography, shopping or browsing), or communicating (e.g. Facebook, e-mail, chatting, dating sites). Three males played games online, and only the participants with ASD (without ID) created content (e.g. on Facebook or a blog). All interviewees with an ID and 2 of 3 with ASD had distressing experiences such as: being insulted online, having false rumors spread, receiving threats or being targets of sexual solicitation. Users with ID have had to rely on a friend, parent or social worker to avoid or repair episodes of cybervictimization.

Access to Internet has opened a wide window of opportunity for people with ID to participate in a virtual community. Nevertheless, education and support are needed to ensure safe and positive Internet use by the population with an intellectual disability.
Session: Online social participation of young people with intellectual disabilities with Martin Molin and Carmit-Noa Shpigelman

Keywords: Intellectual disability, Internet, social participation, social media, online networking

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*Speaker

Overview of the policies implemented

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Within the European Union, each country has developed its own policy. One of the responses that have been implemented in some countries has been a quota scheme. We analysed the country's reports to describe more precisely in which country such a system is currently implemented and if so, what are the characteristics of these schemes. We identified three different categories of countries.

The first category regroups countries (France, Germany, Czech Republic, Romania, Slovakia and Slovenia) which have endorsed a quota scheme approach both for private and public sectors. This involved for employers which do not respect the quota to pay monetary penalties. The amount of these penalties as well as the way to respond to the obligation and the level of the quota vary from one country to another.

The second category regroups countries (Portugal and Ireland) which have set a target for public employers. In Ireland there is a target of 3% of workers with disabilities employed by public employers. In Portugal, the target is applied on recruitment. According to the number of positions open by a public employer, a percentage of it should be reserved for persons with disabilities.

The third category regroups countries (Finland, Netherlands, Sweden and United Kingdom) which do not have a quota scheme. Some of these countries gave up their quota scheme (UK) and in others; there is currently a discussion to implement such policy (Netherlands). To be noted, in UK, there is a public sector equality duty.

However, during the discussion of the research group, it has been difficult to identify which kind of policies might be the most effective to increase persons with disabilities participation to the open labour market as few data are available and as beneficiaries of these policies varies from one country to another. All countries have adopted and/or revised their non-discrimination law in the past decade.

[*]Speaker

The use of photovoice in research involving people with intellectual disabilities

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Although photovoice is increasingly used in research involving people with intellectual disabilities (ID), the number of studies is still limited (for example: Akkerman et al. 2014; Booth & Booth 2013; Jurkowksi 2007; 2008). In a comparative analysis of nine studies involving research with people with ID different approaches of photovoice were detected. For example, the studies diverged in how the participants were informed and trained in photovoice (individual or collective). There was also a variation concerning the level of assistance during the photovoice process in the studies . So, the best way to use photovoice remains unclear. The question arises under which conditions photovoice best enables participants with ID to express themselves?

We developed a guided approach in a study involving twelve people with ID. The aim of our study was to explore the usefulness of this guided approach aiming to reveal the voice of people with ID. Participants were asked to photograph people and places in their direct neighbourhood which were of importance for them. The researcher walked together with the participants through their neighbourhood. In some cases participants found it difficult to take the photos themselves for instance because they had difficulties in handling the camera Or in making proper photographs. In those situations the researcher made the photo for them, taking care that the participant always determined the topic and the angle of their photos themselves. In the subsequent interview participants responded in an individual way to the photographs made to underpin the story they wished to tell.

Our research showed that the application of photovoice should be customized for each participant individually, in order to help them to tell their stories. For example, some participants were very able explaining the relation between the photographs and the stories they evoked during the interview. For other participants this was more difficult. But because of the guided photovoice walk together with the researcher through their neighbourhood they all were able to reveal the stories they wanted to tell.

Keywords: Intellectual disabilties, photovoice method

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*Speaker

Digital objects as mediators of new experiences for students with disabilities

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This research aims to underline the manner in which digital technologies take part to school activities of student with disabilities. Its main focus is about the test of a specific note-taking digital device within the regular school environment in France. It underlines the different types of valuation or evaluation made by the various participants and their direct influence on further action. Additionally, the research implies that students with disabilities are an acting part of the devices design.

An ethnographical fieldwork, through participant observation and interviews with 40 children and young students with disabilities, was used in order to better understand how technology relates to disability. Doing research with children and young people asked the researcher some methodological innovation, but the data were mainly organised through the analysis of categories and categorizations that could appear inside discourses and in action. Moreover, an analysis of valuation and evaluation practices (Lamont, 2012) was made.

The major findings of this research highlighted a multiple level of evaluation. Firstly, the professionals of education and care imagined the adequacy between the device and the students' needs. They chose to recommend it towards their students or, on the contrary, to disapprove it. Secondly, students also participated to this process, from expressing directly their vision about the device to partially or completely integrating it to their study and even leisure actions. Finally, the research allowed seeing accessibility of digital technologies as a special form of affordance (Gibson, 1977). It also made a direct connection between ethics of care (Tronto, 1993), identity and digital objects as mediators of new experiences.

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[*]Speaker

Challenges for inclusive education in France : from expectations to practical modalities

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Since the French disability law in 2005, all disabled children have the right to follow education in a common school together with non-disabled children. This law is part of an international agreement that promotes inclusive education. The device is decided by the Maisons Départementales des Personnes Handicapées and admits several forms of inclusive education: in a regular classroom with or without additional help or special instruction; in a specialized classroom in a regular school, or school facilities in socio-medical establishments. These forms of education are not exclusive and combinations are possible. Between 2000 and 2010, the percentage of children who benefited from these forms of education device increased from 50% to 72%.

This special education system needs cooperation between new actors from different social worlds (Strauss, 1978): educational, medical, social, psychological, sanitary, administrative, familiar, which, for some, were built historically in opposition. (Vial, 1990; Mazereau, 2001).

In our study we were interested how this cooperation is organized and operates.

We conducted an ethnographic study based on observations of different class situations: specialized classes in regular schools and regular classes with one or two disabled children. We also conducted interviews with schoolteachers, school directors, special needs assistants, and parents. Finally, we conducted observations of teachers' meetings at the Ministry of Education.

Our analysis doesn't confirm Dubet's theory of "the decline of the institution" (2002). On the contrary; it shows that the actors have a real vocation for their profession and a strong motivation to succeed inclusive education of disabled children. Yet, our research demonstrates a great gap between different social worlds of the inclusion system. On the one side, the world of administrative actors who, despite a huge workload, show a strong cohesion and consider inclusion to be of great value. On the other side, the world of teaching professionals who have to manage numerous constraints and difficulties in the classrooms, and deal daily with concrete adaptation problems, strategies and readjustments in order to respect as much as possible the

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inclusion objectives.

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Keywords: Inclusive School, Participation, Cooperation

Living in residential care facilities and choosing one's home: a choice under constraint?

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Issue

We are interested in the choice of place of residence for adults with disabilities who don't work and who live in residential care facilities in France. In France institutions run by medical or social authorities have been favored for a long time. Today residential care facilities and nursing home still represent a significant solution for people whith disabilities. They welcome many more people as home care services.

We want to understand the arbitration modes and priorities established by residents when they enter the institution. Does the tension between supply and demand for residential places force the choice of people? What are the limits of margin of decision and action of each? Our question is not one of choosing between life at home and life in institutions but of the choice of the institution.

Method

We conducted interviews with 81 adults who have a mobility impairment, who don't work and who live in residential care facilities. They live in 10 different residential care facilities in 2 French Regions, the Ile-de-France, a urban region and the Haute-Normandie, a more rural region. During the interviews, the questions focused on their residential trajectory and on their feelings about their entry in institution.

Results

The people we met didn't have the same level of knowledge of the offer.
The low supply limits the margins of decision and action. The residential trajectory is mainly suffered. People often had few alternatives to their current institution. However, the family proximity is a key element. The characteristics of the institution (size, urban or rural localization, architectural features, profil of other residents) are important factors but only on a second time.

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The reception of disability policy in France: a life-story perspective on policy change

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French disability policy has undergone important transformations in the past decades, leading to a complex mix of orientations, between protection, compensation and antidiscrimination, drawing on different approaches to disability (Chauvière, 2003 ; Winance, Ville et Ravaud, 2007). The aim of this paper is to demonstrate the relevance of a life-story perspective (based on biographical interviews with ordinary people) to tackle the evolution and the complex contemporary reality of disability policy (Engel et Munger, 2003 ; Shah et Priestley, 2011). I use biographical interviews as a way to trace policy reception, defined as the processes by which a given public policy is perceived, appropriated and mobilized by its target population, and by which it produces both material and symbolic effects on the latter. Drawing on 29 interviews with persons with visual or mobility impairments, the paper distinguishes two types of (both methodological and analytical) uses of life-story research in this perspective. First, the comparison of individual life stories taken as a whole helps identify structural tendencies in policy reception: the extent of the policy change can be documented by the comparison of the life-stories of different generations of people, while the comparison of the life-stories of men and women hints at structural gender differences, for example. Secondly, the more detailed thematic content analysis of the interviews sheds light on the reception of specific policy devices as well as various forms of resistance and claim-making. The case of disability policy thus reveals how much can be learned about a policy by radically decentering the focus from its institutions and listening to the diverse experiences of its target population.

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The functional family in the CRPD

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On December 13, 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD). The adoption marked a historical event which symbolized in many ways the acceptance of people with disabilities into the family of the "human being." The intensive involvement of organizations of persons with disabilities in the drafting process, led to the clear dominance of the social model in the construction of the conventions discourse. The combination between the social model and existing liberal human rights narratives focused on the dominance of accomplishing and stressing the autonomy of persons with disabilities. In my paper I shall examine the effect this conceptual comprehension of autonomy had on the representation of the family with in the CRPD. As shall be presented the families roll of care and support was systematically reduced and devalued throughout the drafting process of the convention, because it was seen to represent the comprehension of the dependent and vulnerable person with a disability. The direct outcome of this process is a minimal presentation of the family in the convention and its construction as a functional vessel in the service of persons with disabilities. I shall examine the outcomes of this construction and effect it has on the conception of persons with disabilities with in the convention and its outcomes on the process of implementation.

Keywords: family, CRPD, human rights, autonomy

Sources of job satisfaction among professionals in intellectual disability services

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This presentation explores sources of job satisfaction among human service professionals working with people with intellectual disabilities. We also explore in what way the organizational context influence these experiences. The data is generated from a larger web survey. A questionnaire was distributed to 640 participants of which 421 answered a standardized question, which yield a response rate on 67 % and 335 respondents answered an open-ended question (52 %), which generated a total of 547 written excerpts. Drawing upon both quantitative and qualitative data a content analysis was used. In order to complement the qualitative analyses descriptive numerical analyses was used. Even though the data shows that the respondents experience heavy work load and psychological strains the vast majority report high ratings on work satisfaction. We argue that it is a fundamental aspect of professionalism to handle this plurality within a specific organizational context. The content analysis revealed that sources of job satisfaction irrespective of organization, is categorized in five different core categories; target group, social rewards, social relations, professional core mission and results/outcomes. We also present and analyze organizational differences in relations to how the response rates are distributed between the five categories.

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Family life with children and personal assistance – a three party perspective.

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The introduction of personal assistance in Sweden in 1994 showed an ambition by policymakers to ameliorate the conditions of persons with extensive disabilities. The legislators expressed a vision of autonomy and integrity, and that persons with considerable disabilities should lead a life like others, including having a family and being a parent. Personal assistance has expanded over the years and in 2014 about 16 100 persons were granted personal assistance in average 124 hours per week. Nearly one quarter of the assistance users live with a partner and about 4 percent with one or several children. The study explores a three party perspective on personal assistance; the users', the family members' and the personal assistants' point of view. What does it mean either to live with personal assistance or to work as a personal assistant when there are children in the family?

The study is based on interviews with six women and two men with extensive physical disabilities and their family members. Four female and one male personal assistant with experience of working in families were also interviewed. The personal assistants have no connection to the interviewed families. Simmel's theories about dyad and triad are found to be useful to understand what happens in different constellations with users, family members and personal assistants.

Having personal assistance enhances the possibilities for parents with disabilities to be active parents. It also relieves family members in different ways. The presence of personal assistants may however restrict the privacy of family members'. Working in families means having several parties to consider and it may be difficult to know where to draw the line as to what the tasks of the personal assistants are.

Keywords: Personal assistance, family life, parents with disabilities, personal assistants, dyad, triad.

[*]Speaker

Sense of belonging of Facebook users with intellectual disabilities

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To date, persons with intellectual disabilities have not been viewed as potential users of social media applications and their voices have not been heard. The present study aimed to describe and understand the personal experiences of Facebook users with intellectual disabilities. Applying a grounded theory approach, interviews and observations were conducted with 20 adults with intellectual disabilities who frequently use Facebook. The qualitative content analysis indicated that the majority of the participants enjoy using Facebook, and it seemed that the online participation contributed to their sense of belonging and psychological well-being. The participants reported that they use Facebook mainly to maintain face-to-face social relationships. At the same time, they experienced stress and frustration due to technical and conceptual difficulties. The findings of the present study emphasize the need to support participation of persons with intellectual disabilities in online social applications and to ensure their safe and fruitful participation.
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Keywords: Intellectual disability, Internet, social media, social participation, sense of belonging, well, being

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Promotion of Inclusive Education in Sweden through use of mainstream technology

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The UNCRPD requires that States Parties recognize the right of persons with disabilities to education and that they ensure an inclusive education system at all levels with the aim to realize this right without discrimination and on the basis of equal opportunity.
Approximately 98.5 per cent of school-aged youth and children are instructed within the mainstream school systems in Sweden. Many pupils encounter difficulties in the school environment that negatively impact their ability to complete their education, and to transition to employment and/or further education. For pupils with neuropsychological, cognitive, psychiatric and neurological impairments and conditions the difficulties can sometimes be overwhelming.

This submission reports on work carried out with funding from the Swedish Inheritance Fund in the project Paths to Employment during the period 2011 – 2014. The project explored how mainstream technology can be used in schools to address barriers so that all pupils can perform on more equal terms, and how collaboration among professionals who work with youth with disabilities both in and outside of school can improve support to individual pupils with disability.

The project was carried out in two secondary schools (approximately 4 700 pupils) in two communities; 215 pupils received individual support. Activities to increase awareness and understanding about cognitive abilities and impairments and how the school environment can support or hinder performance were carried out at the start of the project. A "technology classroom" equipped with mainstream technology (e.g. microphones, interactive whiteboards, computers, tablets, iPads, web-based platforms, MP3, smartphones with apps) was used to reduce barriers so that all pupils could perform better on more equal terms. Specific non-stigmatizing individual support was offered using mainstream technology after assessment of need using a validated interview instrument for assessment of adjustments needed in the school environment.

Collaboration among professionals working with youth with disabilities both in and outside of school was set up to better assist pupils receiving individual support to transition from secondary school to employment or further education.
Project results were positive and national information activities, including setting up a dedicated website, were carried out to inspire other communities.

Keywords: Inclusive education, mainstream technology, cognitive disability

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[*]Speaker

Victor, the Wild Boy of Aveyron (c. 1788 – 1828), and the Rise of Special Education in Modern France

Natalia Starostina * [1]

[1] Young Harris College – Department of History, 1 College Street, Young Harris College, Young Harris GA 30582, United States

The paper examines the legacy of Jean Marc Gaspard Itard (1774-1838) as one of the founders of the special education studies. Itard, a physician, spent four years educating Victor, a feral child, who was found in a French forest.After being captured by hunters, Victor tried to escape several times, but eventually accepted human companionship. Victor lived and acted as an animal: he had no clothing, did not understand language, and ate only roasted or half-burned potatoes, raw chestnuts, and walnuts. Contemporaries regarded Victor an "idiot," and, according to the customs and beliefs of the time, assumed that "it is useless to combat idiocy." Doctor Itard brought Victor to Paris and spent several years trying to teach him language and to help him to become integrated in a human society. Itard was not entirely successful: Victor had only learned several words and never fully comprehended French. On a positive note, Victor's fine motor skills became improved, and he actually developed a sense of certain friendship with people who were taking care of him and learned to communicate with the people around him. At the same time, the story of Victor inspired an intense debate about the importance of language for educating a child and also showed that mentally disabled people needed to receive medical attention and that progress in treating their condition was possible. Working with Victor became an important step towards developing philosophy and strategies for working with mentally disabled people and deaf-mutes. An experience of Itard was important for understanding French society during the French Revolution. Itard believed that empathy was the essential characteristic of a human being, and was disappointed that Victor did not develop much empathy.The story of Victor is reflected in several primary sources. A very valuable account of Victor comes from the text written by Itard himself in 1801 and now available in a digital form from the University of Ontario's library.

Keywords: Jean Marc Gaspard Itard, Victor, a "feral child, " deaf, mute, the rise of special education

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*Speaker

Mapping the Representation of Disability in the Museum Environment

Megan Strickfaden [*] [1], Janice Rieger [2,3]

[1] University of Alberta (UofA) – Canada
[2] University of Alberta, Canada (UofA) – Canada
[3] Queensland University of Technology (QUT) – Australia

Material cultural studies questions societal issues through material things. In the case of this study, we use the museum environment and its relationship with how disability is represented as a means to exploring contemporary society's notion of disability. Museums have been producing and communicating knowledge for over 600 years and yet museums have only recently come under critical examination (Greenhill, 1992). Some interrogation of how disability is represented in museum environments has been conducted (Sandell, 2007; Sandell et al, 2010); however, a more holistic lens that considers representation as relative to the built environment and the messages displayed has never been studied. Our work looks at representation as any and all references (physical, textual, explicit and implicit) that are present within a museum including physical access (to place and space) and content (objects, didactic materials). This work is framed by theories that complement a more holistic approach and focus on the museum as a complex 'material' network where human and nonhuman actors come together to create a representation of disability. Two in-depth case studies conducted in Canadian museums that focus on disability content are the focus. The case studies involve deep object analysis (Hodder, 2003) whereby the space (exterior, interior) and displays are examined for overt or implied content related to disability. By unpacking how disability is represented through the museum-an influential institution where knowledge is both produced and consumed-insights into how contemporary society engages with and constructs disability is revealed. For instance, the representation of disability within museums is sometimes very explicit whereas other aspects of disability are barely present because these are related to cultural memories of silence, loss and forgetting (Connerton, 2006). This presentation promises to be visually rich with the aim to provoking alternate viewpoints around the role of objects and how disability is representative of questions and issues related to contemporary society.

Keywords: accessibility, built environment, consumption, cultural memory, didactics, material culture, object analysis, production

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[*]Speaker

I want a family too! Adoption of children with disabilities in Hungary

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The Hungarian Child Protection Act, according to international conventions, prefers the out-of-home care of children in families, instead of institutional settings, excluding children with disabilities, who are, refering to the international empirical data (Argent 1998, Bunt 2014, Egbert-Lamont 2004, Gallinger 2012, Glidden 2000, Goetting-Goetting 1993, Grant-Thomas 2013, Macaskill 1988, Marcenko-Smith 1991, Mckenzie 1993, Rosenthal 1993, Unger-Deiner-Wilson 1988), one group of the so called hard to place" children. The aim of our state-aided empirical study (OTKA K111917) is to reveal the characteristics of the families that deliberately adopt children with disabilities. This basic research uses qualitative and quantitative approaches, in the theoretical framewok of (Feminist) Disability Studies. Implementing the participatory research in various ways, member of the research group is an adoptive father of a disabled child, a leader of an NGO that coordinates the adoption of children with Down Syndrome, and a 21 year old man with Down Syndrome who lives in an adoptive family. First element of the process was a questionnaire with 52, open ended and closed ended questions. 23 answers were analysed, that is, according to the statistical database, 10-25% of the full sample. As a second step, 15 narrative interviews are made with adoptive parents and in the last sequence 7 focus groups are conducted. The focus groups involve all the relevant stakeholders of the adoption process: experts of the governmental and non-governmental organisations, parents who have place their child for adoption (and their other children), the adoptive children, and their siblings in the adoptive family.

As a result, we can get closer to the biographies of the parents who decide to adopt, and we can identify potential groups that can be encouraged to adopt. We better recognize the needs of families, their pleasures and difficulties after the adoption, that can help to establish adequate supports in their everyday lifes. These empirical evidences can also lead to a legislation reform, and more children with disabilities can live in families.

Keywords: adoption, children with disabilities, participatory research, Disability Studies, Feminist Disability Studies

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Citizenship in action: Swedish disabled people claim 'Full Participation. Now'

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In his lecture about Citizenship and Social Class, T.H. Marshall noted that 'societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspiration can be directed'. The ideal of citizenship is not neutral, however, and various feminist scholars have called attention to the fact that citizenship tends to be tailored to the situation of able-bodied, adult, heterosexual and full-time employed males. As a consequence, people who do not fit this template risk finding themselves in a position of 'second class citizens'.

This paper investigates how citizenship is continuously being imagined, reworked and negotiated in different societal arenas and how people claim their right to participate in society and to be recognised as valuable members of their society. The study focuses on the case of disabled people in Sweden claiming their right to full citizenship.

The empirical analysis is grounded on an online blog called 'Full Participation. Now' which was created five months prior to the 2010 general elections in Sweden. The blog's aim was to get the politicians' attention to the issue of full citizenship for persons with disabilities and the analysis shows how citizenship for disabled people is being (re-)imagined by bloggers who point at discriminatory practices at political, community and personal level. The analysis also shows how citizenship is negotiated by the bloggers who imagine citizenship in various – and sometimes contradictory – ways. Finally, the analysis indicates that the ideal of citizenship found in the blog posts not only develops in relation to the political arena but also in relation to everyday activities and experiences.

Keywords: disability, citizenship, Sweden, blog, participation, rights

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Universal and special conditions for advocating disability rights: from the experiences of Japan and Korea

Ryoko Takahashi *† 1

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In the process of formulating policies for the disabled, more emphasis is being placed on participation by the disabled themselves both domestically and internationally. Active disability rights movements are emerging in many countries.

I previously researched on the conditions for successful advocacy that promotes the participation of disabled people in the field of welfare policymaking, reviewing and comparing the advocacy of organizations consisting of disabled people in Nordic countries, United States and Japan. This discussion covers the organizations' history, fundraising strategies, ways of participating in the policymaking process, relationship to the government, as well as their role and influence. Universal conditions for participation by the disabled in every country are as follows; the role of disabled people's organizations to be a community for them to have an identity as a member of society is very important especially when we are dealing with a familistic welfare system. Definite strategies and international networks are required to respond to the domestic welfare system and gain power to negotiate with and protest against the government.

Now the aim of this report is to confirm these conditions and add several factors to develop active and effective disability rights advocacy in East Asia. For this purpose I will review and compare the advocacy work of disabled people's organizations in Japan and Korea. There are similar welfare system and familistic cultural value, and recently strong disabled citizen's movements in both countries. I also focus on the National Human Rights Commission of Korea established in 2001 as a national advocacy institution for human rights protection and examine its function in welfare policies. Lastly I will mention the significance of legislation of Non-Discrimination Act for the disabled people in Japan and Korea.

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Organization and impact - self-advocacy in Sweden

Magnus Tideman * [1]

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Aim: In the last decades young adults with intellectual disability (ID) have begun to self-organize in order to increase power over their own lives and remove barriers to their social participation in society. This study aimed to further understand the new forms of self-advocacy in Sweden by describing and analyzing the characteristics and organization of the movement and its activities and by analyzing the meaning for the members and the influence for identifications, self-determination, relations and daily life. **Method**: A national mapping identified more than 60 self-advocacy groups. Case studies of 4 organizations, selected to reflect organizational diversity, were conducted using interviews, focus-groups, observations and document review. **Findings**: Variability in organizational forms and size, show how self-advocacy groups can be everything from totally independent to be controlled by parents or staff. Despite this the interviews showed that the self-advocacy groups have an important impact on the lives of their members. Participation in self advocacy groups open up for new roles and identities and strengthen control over every-day life. Self-advocates understand self-advocacy primarily in terms of their participation in the self-advocacy group and through the value they experience through achieving independence, control and social connections with each other and outsiders. The most independent groups have in addition to that mounted resistance to society's views and treatment of people with intellectual disability and the traditional ways of delivering services. **Conclusions**: Self-organized activities can be understood in terms of resistance against the society's views and treatment of people with ID and against traditional ways to offer and organize support and service. The self-advocacy movement in Sweden is slowly beginning to influence the way society regards people with intellectual disability, and reshape support services to enable greater service user control.

Keywords: Intellectual disability: self, advocacy: organization: impact: Sweden

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*Speaker

Growing up with disability in Norway – family perspectives

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Background: Since the 1960s, the policies on disabled children in Norway have rejected the idea of institutionalisation. All children should grow up with their family but this is expected to take place in a division of labour between families and the welfare state – the welfare state is supposed to provide the services needed to make both the childhood and the family life as normal as possible. Aim: The aim of this presentation is to scrutinize the division of labour between families and the welfare state for families with disabilities growing up after the major inclusion reforms in the 1990s, from the perspective of families. Methods: Longitudinal survey (n=603) and interview (n=31) data on families of disabled children born 1993-95, with five waves of data gathering (1999, 2003, 2006, 2009 and 2012). Results: Results are conflicting. On the one hand, responses to questions on service quality suggest reasonable satisfaction. On the other hand, parents express substantial frustrations regarding their interaction with public agencies and in particular access to services. Discussion: The main part of the presentation is the discussion on how to understand the conflicting results. It is argued that even in an advanced welfare state like Norway, barriers to access is tacitly used to produce disincentives to seek public support. Measures to avoid exploitation of the system have thus substantial impact on the everyday life of the families for whom the services are intended.

Keywords: Children, family, service systems

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[*]Speaker

Hate speech targeted at disabled persons

Janikke Solstad Vedeler [*][1], Terje Olsen [*][†][1]

[1] Nordland Research Institute – Norway

British and American research has examined the phenomenon of hate speech and disability (e.g. Beadle-Brown et al 2014, Corker 2000, Shelly 2003). This body of knowledge shows that disabled persons are the target of hate speech and hate crime to a larger extent than other citizens. Being the victim of hate speech may cause serious personal problems as well as limitations in people's lives. Furthermore, hate speech may create a political situation of "oppressive silencing" (Corker 2000) in which particular groups of citizens withdraw from societal participation in fear of stigmatizing and discriminatory utterance and practices.

The prevalence of and experience with hate speech towards disabled persons have so far not been examined and addressed in the Nordic countries. Our study examines the following three questions: To what extent are disabled persons exposed to hate speech? What types of hate speech do they experience and in what contexts, and what are the consequences of experiencing such utterances? Which preventive measures could be implemented? To shed light on these questions, the study includes a survey and qualitative interviews that will be implemented in the spring of 2016. The survey is based on a British questionnaire developed by Beadle-Brown and her colleagues (2014). The survey will measure the prevalence and scope of hate speech towards persons with different forms of disabilities. Interviews with disabled persons who have experienced hate speech will explore understandings of this phenomenon as well as personal experiences. Interviews with representatives of disabled persons' organizations and other relevant milieu will be carried out in order to address preventive measures.

The presentation will provide preliminary results, comparing the Norwegian results with those obtained in England.

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Tracing life trajectories using sequence analysis to identify how disabilities impacted on people's social inclusion in past society

Lotta Vikstrom * [1], Helena Haage *

[1], Erling Häggström Lundevaller *

1

[1] Umea University (SWEDEN) (Umu) – SE-901 87 Umeå, Sweden

This study traces the life trajectories among young individuals with and without disabilities who experienced the same historical environment (the 19th-century region of Sundsvall, Sweden). The aim is to explore whether and how their trajectories differed by disability and gender as regards vital events in life, such as taking up work, marrying and form a family. Such events are indicative for people's inclusion in social life and society, but there is poor knowledge about these issues in history. Disability studies show that disabilities limit individuals' chances to participate in today's labor market. Theoretical explanations suggest that this is not only due to the impairment itself, as perceptions about normalcy tend to render a stigma that promotes exclusion on the basis of disability. Having unique access to individual-level data (parish registers digitized by the Demographic Data Base, Umeå University, Sweden) enables us to test this theoretical notion historically by employing sequence analyses of 8,874 individual trajectories. The data allow observation over lifetime (here from 15 years of age until 33) and show the presence of disabilities. This helps to clarify if getting a job, finding a spouse to marry and form a family with were infrequent events due to disability. Our first results reveal that this was the case and indicate that a stigma added to make work and family less frequent among disabled individuals albeit some differences by type of disability and gender are found. The sequence analyses generate novel findings on how disabilities impacted on people's inclusion in past society, in providing a holistic picture that accounts for several events among a substantial number of cases. Only being able to conduct such analyses of individuals living 150-200 years ago makes our study innovative, as quantitative methods are under-used in both disability studies and social history.

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*Speaker

Towards cross-national convergence of disability politics? A comparative study on the involvement of disability organisations in UN CRPD implementation processes in European countries

Anne Waldschmidt * [1]

[1] University of Cologne, International research unit Disability Studies (iDiS) – Universität zu Köln, Humanwissenschaftliche Fakultät Frangenheimstr. 4 D-50931 Koeln, Germany

The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) has acknowledged the relevance of organisations representing persons with disabilities by obliging States Parties to consult with and actively involve these organisations in CRPD implementation processes at national level. Against this background this presentation investigates the involvement of disability organisations in national policies that have aimed at ratifying and, in a further step, are about to implement the Convention. It uses empirical data generated within the EU funded research consortium DISCIT and draws on 84 guided informant interviews with national experts of disability policy and representatives of disability organisations in the nine European countries Czech Republic, Germany, Italy, Ireland, Norway, Serbia, Sweden, Switzerland and the United Kingdom.

This presentation uses a qualitative method of analysis, for its analytical concept it refers to the approaches of international relations, transnationalism and policy convergence. It will first investigate in what ways national disability organisations have become engaged in efforts towards achieving CRPD ratification in their countries and how these organisations have in recent years been involved in implementation processes. Second, the interview data is used to explore the impact of the CRPD with regard to national styles of political deliberation and decision-making. This national comparative study intends to answer the question whether the CRPD has increased disability organisations' chances to exercise influence on behalf of persons with disabilities and what practices have resulted from these opportunities. It concludes with identifying a trend towards cross-national convergence of disability politics in the age of the United Nations' Convention.

Keywords: UN Convention, human rights, disability rights advocacy, disability politics, Europe, policy convergence

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*Speaker

Different Developments in Supported Employment policies

Angela Wegscheider * [1], Stefanie Breinlinger

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The proposed presentation focuses on recent developments in labour market policies with a special focus on supported employment programmes. We compared supported employment policies and programmes in Sweden, Germany, The Netherlands and The United Kingdom (England) in reference to Austrian's federal state Upper Austria.

Supported Employment in our view ranges from publicly subsidised forms of employment for people with disabilities at sheltered work places to work places on the regular labour market supported by on-the-job-training and follow-up support. We considered supported employment forms which are subject to full social security. Most of those countries have been reforming their programmes to increase mainstream labour market participation of the target group and to reduce expenditure on disability benefits. In our study, we identifies strengths and weaknesses of the various employment schemes and juxtaposes outcomes of recent reforms experienced in said countries.

First, in the study the social law and labour law context of Supported Employment was examined and the specific arrangements were analyzed concerning aspects like funding, payment, accessibility, support process and transition to the regular labour market. Second, interviews with academic experts and professionals revealed contradictory effects of reforms in supported employment targeting inclusive employment. Our results show that Service providers deal differently with an environment of cuts in funding by an austerity policy and a tight labour market. When sheltered work places in social enterprises were reduced, a creaming effect occurs: while the most job-ready persons within a target group are employed on the mainstream labour market, an increasing number of people with disabilities stay out of work and employment, most of them inactive at home with basic social transfers.

Keywords: Supported Employment, comparative study, reforms, active labour market policy

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*Speaker

Evaluating the German Federal Law of Equal Treatment of Disabled Persons – methods and results

Johanna Wenckebach [1], Diana Ramm [*] [1], Felix Welti [1], Lilit Gregorian [*]

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[1] University of Kassel – Germany

The German federal law of equal treatment of disabled persons (Behindertengleichstellungsgesetz des Bundes, BGG) came into effect in 2002. An evaluation of this law was required by the national plan of action for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and was published by Welti et al. in 2014.[1]
Project evaluation objectives were to estimate whether the needs of disabled persons are met and whether the instruments were apt to achieve the aims of the law. Jurisprudential analyses in combination with surveys where used for this research.

The presentation will give both an explanation of the socio-scientific research approach and the data gained, as well as the outcome of the legal analysis based on that data.

I. Social science (Diana Ramm)

In it's socio-scientific research approach, the evaluation-team performed a survey among government agencies dealing with the BGG. Employees of public health insurances and the federal employment agency were asked to complete a questionnaire. Organizations of disabled people were also included in our research approach. These were surveyed by a web based barrier-free questionnaire.

II. Disabilty, Equality and Human Rights Law (Dr. Johanna Wenckebach)

Legally, the evaluation has focused on the legal questions arising from the data provided by the social science research done in advance. Both legal literature and relevant case-law of German Courts as well as the ECJ have been analysed.

III. Main results (Ramm/Wenckebach)

Main results have been e.g. that

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[*]Speaker

- laws on inclusion and participation still have a lack of publicity;

- class action suits have barely been used by disability organisations in practice; instead, the researchers suggested to implement legal rules on arbitration based on the Austrian legislation;

- there is a need to harmonize central legal definitions of disabilty" and discrimination" according to the CRPD in German law; "reasonable accomodations" (Art.5 CRPD) are not explicitly implemented into German law yet.

The impacts of BGG, however, were valuated positively. Results also indicate that there might be some shortcomings in regard of accessibility. A reform of BGG is in the law-making process now[2]. The presentation will therefore give an outlook on which suggestions of the interdisciplinary researchers might be enacted in order to make the German law more coherent with the CRPD.

http://www.bmas.de/DE/Service/Medien/Publikationen/Forschungsberichte/Forschungsberichte-Teilhabe/fb-445.html

http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Meldungen/2016/gesetzentwurf-zur-weiterentwicklun des-behindertengleichstellungsrechts.pdf?__blob=publicationFile&v=2

Keywords: CRPD, reasonable accomodation, evalutation, class action, arbritration, accesibility

Social activism of persons with disabilities in Poland - development and the current state of new social movements

Agnieszka Woynarowska [*][†] [1,2], Jolanta Rzeźnicka-Krupa [*] [‡] [2]

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[2] University of Gdańsk – Poland

Political changes taking place in Poland since 1989 after the collapse of communist meta-narration held a promise of building a democratic, pluralistic society. Moreover, the issues which so far had been neglected or presented in a biased way due to monocentric social order and political censorship now stand a chance of coming into public discourse. Due to democratization, a large number of minorities have been given the possibility to articulate their needs and fight for their rights. Developing democracy together with its institutions and mechanisms based on the idea of human rights and equal opportunities for various social groups have led to the occurrence of the phenomenon of discourse of diversity, identity and the politics of voice.[1] The socio-political transformation which started in early 90s has also activated social movements of persons with disabilities the philosophy of which was based on the concept of Independent Living. These social movements have played a key role in introducing changes to Polish legislation so that the idea of integration, normalisation, equal opportunities for education and employment as well as active participation in social life and culture could become possible.

The objective of our presentation is to provide a description and analysis of social movements of persons with disabilities in Poland. We'd like to focus on their diversity, goals, assumptions as well as discuss some of the ongoing projects in Poland. The analysis consists of two dimensions:

1. the presentation of socio-political and cultural conditions underlying the formation of social rights movements of persons with disabilities in the light of political changes (from socialism to democracy)

2. the presentations of the aims of current social rights movements of persons with disabilities in the context of UN Convention on Rights of Persons with Disabilities ratified by Poland in 2012; ongoing social campaigns and change demands for the new, conservative government.

See e.g. Gustavsson, A., Zakrzewska-Manterys (Eds.), Upośledzenie w spolecznym zwierciadle (Disability in the Social Mirror), Warszawa 1997, Żak".

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In Focus: Blind Photographers Challenge Visual Expectations

Megan Strickfaden * 1

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Photographers who are blind: an oxymoron? Yes and no. Yes, because the majority of world thinks about blindness as the experience of being in blackness, devoid of any sensation of sight. No, because blindness is precisely and distinctly not about blackness. It is a little known fact that the majority of people who are categorized as blind are actually partially sighted and they can see a great deal. Yet, in general, society continues to focus on what people cannot see rather than what they can see. Blind photography, therefore, provides sojourns into the grey areas of blindness. These grey areas may be described, for example, as sight meeting sightlessness, light meeting darkness, and colours meeting blackness. Blind photography is a celebration of what people can see, which leads to provoking audiences to take part in alternate ways of thinking about the world and disability. Photographs created by blind people are made possible through contemporary technologies where people are willing to share their experiences and tell their stories of ability. In the case of photography, seeing in less traditional ways is the specific ability that is presented. This presentation explores the conceptual reality of blind photography as a means to challenging visual expectations. Three significant aspects emerge when focusing on blind photography: 1) photographers, 2) photographs and 3) audience. These aspects are entwined in a performance that results in powerful statements about sight, sightlessness and the built environment, which opens things up for people to consider and experience the world 'in focus'.

Keywords: ability, built environment, individual experience, performance

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*Speaker

Learning from a Village: The Materiality of Disability

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De Hogeweyk, a 23-townhouse village development near Amsterdam in Weesp open since 2007, where people with mild to severe dementia can safely walk and bike streets, grocery shop, attend theatres and other social hubs, prepare their own meals, have the opportunity to iron and do their laundry. Their independence is possible because the 1.6-hectare site is actually a large-scale nursing home designed to look like a village, but with only one, secured, exit. At De Hogeweyk, groups of six to seven residents live together in one of seven different townhouse styles. Each is designed and furnished to reflect different cultural lifestyles, including upper class, traditional, Indonesian and cultural. For five days last February, Megan Strickfaden and Nicole Gaudet were the first researchers along with filmmaker Steven Hope ever to gain liberal access to this world-renowned facility dubbed "Dementia Village." The result is a 33-minute ethnographic documentary film called 'Dementia Care by Design' that highlights the relationships that de Hogeweyk's residents have with their caregivers and the built/designed environment of the village. Since this was an ethnographic documentary film project, there was no predetermined storyline. Instead, the research team and filmmaker recorded as many details as possible for a critical understanding of what works and what doesn't work in the village. Wandering the site unsupervised, the team engaged in ethnographic research and shot footage from the moment residents awoke until bedtime resulting in greater than 12 hours of video footage, conducted nine interviews with staff and family, shot nearly 1,000 still photographs, and recorded 60 pages of field note observations. Analyzing the textual and visual data and subsequently editing the film, several themes emerged that appear to be contributing to residents' well-being. These included continuity, choice, memories, multi-sensory stimulation, indoor-outdoor experiences and everyday activities occurring during the natural flow of time. Format: screening of the 33-minute ethnographic film 'Dementia Care by Design' bookended by a lecture and discussion [note that this presentation can also be done through the screening of an abreviated 8-minute film on de Hogeweyk but it would not have the same impact]

Keywords: material culture, film, quality of life, choice, independence

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*Speaker

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8.15 - 9.00	Registration and coffee (Auditorium G)			
9.00 - 9.30	**Welcome address** by Anders Gustavsson, Organising Committee; Astrid Söderbergh-Widding, Vice-Chancellor of Stockholm University; Malin Ekman Aldén, Acting director-general for the Swedish Agency for Participation and Isabelle Ville, President of Alter (Auditorium G)			
9.30 - 10.30	**Key-note speaker Anne Marcellini, Associate Professor Université de Lausanne** The unexpected developments in disability sports. But what does all this mean? Chair: Rafael Lindqvist (Auditorium G)			
	Auditorium G	**Room P 216**	**Room P 224**	**Room P 232**
10.45 - 11.45	**Inclusion, Participation and Human Rights** Chair: Rafael Lindqvist Growing up with disability in Norway—family perspectives **Jan Tøssebro** And so it was—later on we found each other directly—a narrative analysis of five you men's experiences of participation by utilising personal assistance **Lill Hultman** Living together in opposition to norms and values of Swedish politics and everyday life—adults with ID living with their parents **Kristina Engwall**	**Disability and Culture** Chair: Anne Waldschmidt Hate speech targeted at disabled persons **Jannikke Solstad Wedeler** In focus: Blind photographers challenge visual expectations **Megan Strickfaden** Victor, the Wild Boy of Aveyron (c. 1788 – 1828), and the Rise of Special Education in Modern France **Natalia Starostina**	**Schools: Between Inclusion and Exclusion** Chair: Jean-Sébastien Eideliman Challenges for inclusive education in France : from expectations to practical modalities **Sofia Rosman and Isabelle Ville** Disability and Inclusive Processes at School. Exploring Conceptual and Interpretative Models from the Point of View of Special Pedagogy **Antonello Mura and Antioco Luigi Zurru** Special educational needs – assessment and categorising processes in an international perspective **Dörte Bernhard and Teresa Sansour**	**First Person Perspectives on Disability** Chair: Louis Bertrand The reclaiming and reconstruction of positive identities in the recovering process by women and men with experience of long term mental distress **Ann-Charlott Timander** Changes in services **Anna Kittelsaa** Complexity and continuity—identity constructions of persons with intellectual disabilities **Anders Gustavsson**

11.45 - 13.00	Lunch (Outside room P216)			
	Auditorium G	**Room P 216**	**Room P 224**	**Room P 232**
13.00 - 14.00	**Inclusion, Participation and Human Rights** Chair: Nora Groce	**Disability and Culture: Representations, Media and Meaning Making** Chair: Michel Desjardin	**Schools: Between Inclusion and Exclusion** Chair: Jens Ineland	**Employment and Disability across Europe: Thoughts from the public sector (First Part)** Chair: Marie-Renée Guével
	Realising the Participation Rights of the Disabled Child: realistic goal or wishful thinking? **Anne-Marie Callus**	Remaking disability in China: The Little People's Kingdom in Kunming (Yunnan Province, China) **Patrick Devlieger**	Schooling pupils with disabilities in France and Cameroon: a comparative analysis **Ernestine Ngo Melha**	Overview of the policies implemented **Darina Ondrusova**
	Evaluating the German Federal Law of Equal Treatment of Disabled Persons – methods and results **Lilit Grigoryan and Diana Ramm**	Perspectives on difference and stigma: researching the lives of people with albinism in Malawi **Paul Lynch** Which theory of disability does transhumanism presuppose? **David Doat**	Experience and forms of uses of disability compensation devices in French universities **Nathalie Le Roux** The inclusive school in Portugal: the perspective of teachers, families and key actors **José Nogueira**	Barriers and facilitators to access paid jobs **Marie-Renée Guével**

	Auditorium G	Room P 216	Room P 224	Room P 232
14.15 - 15.15	**Inclusion, Participation, Citizenship, and Human Rights** Chair: Lennart Sauer Living in residential care facilities and choosing one's home: a choice under constraint? **Noémie Rapegno** Family life with children and personal assistance – a three party perspective. **Viveca Selander** I want a family too! Adoption of children with disabilities in Hungary **Anikó Sándor**	**Disability and Culture: Representations, Media, and Meaning Making** Chair: Patrick Devlieger Artistry and Disability – Doing Art for Real? Affordances at a Daily Activity Centre with an artistic profile **Helen Knutes Nyqvist and Marie-Louise Stjerna** Inclusive Music and the Capabilities Framework: contextualising the experiences of inclusive music in the lives of children and young people with disabilities **Susan Levy** Mapping the Representation of Disability in the Museum Environment **Megan Strickfaden**	**Schools: Between Inclusion and Exclusion** Chair: Anders Gustavsson Are the so-called Students with Special Educational Needs scarcely prosocial by nature or by culture? **Alessia Travaglini** Students with disabilities and their experiences of higher education- a comparative institutional analysis of equal opportunities in Sweden, The Czech Republic and the United States **Ulrika Järkestig Berggren** Digital objects as mediators of new experiences for students with disabilities **Cristina Popescu**	**Employment and Disability across Europe: Thoughts from the public sector (Second Part)** Chair: Marie-Renée Guével Emergent solutions and challenges **Johanna Gustafsson** Different Developments in Supported Employment policies **Angela Wegscheider**
15.15 - 15.45	**Coffee Break** (Outside room P216)			

Conference Programme – Thursday 30 June

	Auditorium G	**Room P 216**	**Room P 224**
15.45 - 16.45	**Inclusion, Participation, Citizenship, and Human Rights** Chair: Karin Sonnander Rights in Transition: The Experiences of Young Deaf People **Bronagh Byrne** Recognising agitated children as disabled in France **Jean-Sébastien Eideliman** The functional family in the CRPD **Liora Roffman**	**Human service organisations and intellectual disabilities** Shared chairpersonship Handle with Care: Staff Experiences of Difficulties working with People with Intellectual Disabilities **Martin Molin, Lennart Sauer and Jens Ineland** Sources of job satisfaction among professionals in intellectual disability services **Lennart Sauer, Martin Molin and Jens Ineland** Knowing, being or doing? Perceptions among human service professionals about quality in day-to-day encounters with people with intellectual disabilities. **Jan Hjelte and Jens Ineland**	**First person perspectives on disability** Chair: Magnus Tideman The experiences of societal participation of people with disabilities: An interview-study among people with disabilities in Finland **Elisabeth Hästbacka** A gender equality analysis of living conditions and participation opportunities for persons with disabilities **Ann Frisell Ellburg** Individual concepts and experiences of adulthood of people with intellectual disabilities in the context of inclusion/exclusion, participation and human rights **Dorota Krzemińska and Iwona Lindyberg**
17.00 - 17.45	**Key-note speaker** **Jan Grue, Professor Oslo University** Now You See It, Now You Don't: Disability Studies in a Disciplinary World. Chair: Rafael Lindqvist (Auditorium G)		
18.00 - 19.00	**Transport to Stockholm City Hall, Centre of Stockholm** (Entrance 20D for busses and wheel chair taxi)		
19.00 - 21.00	**Reception at Stockholm City Hall** hosted by the City of Stockholm		

Conference Programme – Friday 1 July

9.00 - 10.00	Key-note speaker Rayna Rapp Professor, Faye Ginsburg, Professor Anthropology Department, New York University. Cripping the Future: Making Disability Count Chair: Anders Gustavsson (Auditorium G)			
	Auditorium G	**Room P 216**	**Room P 224**	**Room P 232**
10.15 - 11.15	**Online social participation of young people with intellectual disabilities** Chair: Claude Normand A Conceptual Model of Factors Leading to the Inclusion of People with Neurodevelopmental Disorders in the Digital World **Claude Normand** Risks and opportunities in new emancipatory landscapes? On young people with intellectual disabilities, Internet use and identification processes **Martin Molin** Sense of belonging of Facebook users with intellectual disabilities **Carmit-Noa Shpigelman** Risks and Benefits of Internet Use by People with Neurodevelopmental Disorders **Claude Normand**	**Inclusion, Participation, Citizenship, and Human** Rights Chair: Eve Gardien Fulfilling the Intentions of CRPD Article 29: Involving People with Disabilities in Public Affairs **Rebecca Irvine** Rights-Holders under the UNCRPD: Challenging Definitions of Disability in Human Rights **Bronagh Byrne** People with support from the Swedish Disability Act (1993:387) – included or in charge? **Susanne Larsson**	**Disability movements, Advocacy, and Identity Politics** Chair: Rafael Lindqvist Advocacy on behalf of those who cannot instruct: Perspectives of English Non-instructed Advocates **Gillian Loomes** Universal and special conditions for advocating disability rights: from the experiences of Japan and Korea **Ryoko Takahashi** Egyptian Disability Movement: Are Voices Heard and Policies Impacted? **Mostafa Attia**	**Innovative Methods in Disability Research** Chair: Berit Berg Of some pitfalls and deadens of participatory applied research: A critical reflection on common principles and techniques of reform within disability service networks **Michel Desjardins** Negotiating consent throughout the research process. Participation on the participant's terms. **Anne Lindblom** The reception of disability policy in France: a life-story perspective on policy change **Anne Revillard**

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Conference Programme – Friday 1 July

11.15 - 11.45	Coffee Break (Outside room P216)			
	Auditorium G	**Room P 216**	**Room P 224**	**Room P 232**
11.45 - 12.45	**Design, Technology and Materiality** Chair: Arvid Lindén Monitoring UNCRPD in a national perspective **Erik Lindqvist and Magnus Lagercrantz** A Design Perspective on Participation Research **Per-Olof Hedvall** Dissecting strategies for creating inclusive societies in twelve western countries, going beyond accessibility concepts and achieving universal usability **Jonas Andersson**	**Gender, Ethnicity and Intersectionality** Chair: Anne Revillard Invisible identities: A critical analysis of intersections of gender, culture and disability in the Maghreb **Paula Campos Pinto** Immigration and disability: Minority families with disabled children **Berit Berg** 'The issue is about her "social capacity"': exploring 'risk' as another category of difference in intersectional analysis in disability research. **Godfred Boahen**	**Disability movements, Advocacy, and Identity Politics** Chair: Jan Tøssebro Towards cross-national convergence of disability politics? A comparative study on the involvement of disability organisations in UN CRPD implementation processes in European countries **Anne Waldschmidt** Organisation and impact - self-advocacy in Sweden **Magnus Tideman** Citizenship in action: Swedish disabled people claim 'Full Participation. Now' **Marie Sépulchre**	**Innovative Methods in Disability Research** Chair: Eva Jepppsson Grassman The use of photovoice in research involving people with intellectual disabilities **Tessa Overmars-Marx** Gruppenbild mit Mensch mit Behinderungen. Studying life-course of people with « rare disabilities » through institutional records **Louis Bertrand** Participation in physical activities for children with physical disabilities: feasibility and effectiveness of physical activity referrals **Katarina Lauruschkus**
12.45 - 14.00	Lunch (Outside room P216)			

Conference Programme – Friday 1 July

	Auditorium G	Room P 216	Room P 224	Room P 232
14.00 - 15.00	**Design, Technology and Materiality** Chair: Martin Molin Communicating and hand(ling) technologies. Everyday life in educational settings where pupils with cochlear implants are mainstreamed **Ingela Holmström** Learning from a Village: The Materiality of Disability **Megan Strickfaden** Promotion of Inclusive Education in Sweden through use of mainstream technology **Terry Skehan**	**Sexuality: a measure for citizenship and inclusion** Chair: Shared chairpersonship An empty arena – on attitudes to and experiences of sexuality education among special school and habilitation service staff in Sweden **Jack Lukkerz** A minority within a minority: Being transgender and having an intellectual disability **Claire Lucille Azzopardi Lane** Sexuality: a risk or a right? Conceptualisations of sexual expression by personnel in disability services **Julia Bahner**	**Disability movements, Advocacy, and Identity Politics** Chair: Paula Campos Pinto The emergence of the public problems of invalidity and blindness at international scale (1918-1939) **Gildas Bregain** Peer counsellors' resistance to ability-centrism : a way for body emancipation **Eve Gardien** Social activism of persons with disabilities in Poland - development and the current state of new social movements **Agnieszka Woynarowska and Jolanta Rzeźnicka-Krupa**	**Innovative Methods in Disability Research** Chair: Louis Bertrand The UN Washington Group on Disability Statistics Secretariat: A New Resource for Research and Practice **Nora Groce** Tracing life trajectories using sequence analysis to identify how disabilities impacted on people's social inclusion in past society **Lotta Vikstrom** Situational Disability - Rethinking disaster relief strategies for disabled people **Friedrich Gabel**
15.15 - 16.15	**Closing ceremony** Anders Gustavsson, Rafael Lindqvist, Isabelle Ville and Anne Marcellini **(Auditorium G)**			
16.30 - 18.00	**Alter Meeting (Auditorium G)**			

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Program overview

Thursday 30 June

8.15 – 9.00	**Registration and coffee**
9.00 – 9.30	**Welcome address** by Anders Gustavsson, Organising Committee, Astrid Söderbergh-Widding, President of Stockholm University, Malin Ekman Aldén, Swedish Agency for Participation, Isabelle Ville, President of Alter
9.30 – 10.30	**Key-note speaker** Anne Marcellini, associate professor Université de Lausanne The unexpected developments in disability sports. But what does all this mean?
10.45 – 11.45	**Parallel sessions**
11.45 – 13.00	**Lunch**
13.00 – 14.00	**Parallel sessions**
14.15 – 15.15	**Parallel sessions**
15.15 – 15.45	**Coffee**
15.45 – 16.45	**Parallel sessions**
17.00 – 17.45	**Key-note speaker** Jan Grue, Professor Oslo University. Now You See It, Now You Don't: Disability Studies in a Disciplinary World.
18.00 – 19.00	**Transport to Stockholm City Hall**, Center of Stockholm
19.00 – 21.00	**Reception at Stockholm City Hall**

Friday 1 July

9.00 – 10.00	**Key-note speakers** Rayna Rapp, Professor Anthropology Department, New York University. Faye Ginsburg, Professor Anthropology Department, New York University. Cripping the Future: Making Disability Count
10.15 – 11.15	**Parallel sessions**
11.15 – 11.45	**Coffee**
11.45 – 12.45	**Parallel sessions**
12.45 – 14.00	**Lunch**
14.00 – 15.00	**Parallel sessions**
15.15 – 16.15	**Plenary session and closing ceremony**
16.30 – 18.00	**Alter Meeting**