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HISTORIES, PRACTICES AND POLICIES OF DISABILITY

International, Comparative and Transdisciplinary Perspectives

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HISTORIES, PRACTICES AND POLICIES OF DISABILITY. INTERNATIONAL, COMPARATIVE AND TRANSDISCIPLINARY PERSPECTIVES

Disability is a multidimensional phenomenon: it is understood as a lived experience, a social practice, a cultural trope and an international policy issue. A growing body of scholars investigates disability as a historical, social, political and cultural construction. In the age of the UN Convention on the Rights of Persons with Disabilities (CRPD), discourses on disability can be traced throughout a multiplicity of histories, narratives, practices and policies. The existing landscape of innovative disability research and political interventions consists of a broad spectrum of theoretical concepts, methodological and empirical approaches and ethical foundations, and draws from the political and social sciences, historical research as well as the cultural studies approaches. Studying disability as a multifaceted object of research raises the following questions:

- How is historical, socio-political and cultural knowledge about embodiment, health, normality, impairment and dis/ability produced and transformed?

- How are theories and concepts of disability translated into empirical methodology (e.g. participatory and/or emancipatory research), and how can disability research and critical disability studies inform general academia and political practice?

- How do individual and social identities, self-conceptions and body images intersect with societal structures, social institutions, identity politics, political governance and cultural representations?

- What are the political, social and cultural consequences of a disability research that relates to general debates on historical legacies, social inequality, post-colonialism, human diversity, fundamental rights, participation, exclusion and inclusion?

This conference aims to contribute to the thriving discourse of international, comparative and transdisciplinary disability research. It offers a platform for debates and conversations between regions, disciplines and theoretical perspectives. It presents an opportunity for exchange between young scholars and senior researchers in disability research and critical disability studies.

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Architecture for defying exclusion of people with disabilities, Swedish accessible housing revisited

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Barriers in the built environment exclude people with disabilities from participating independently in the surrounding society. Since the mid-1960s, architectural designs have been subject to special regulations in the Swedish building code, originally focusing on access for wheelchair users to public buildings. In the mid-1970s, this focus converged with the first Swedish disability policy and "accessibility for people with locomotory or cognitive problems" of the building code was coined. Building initiatives by organisations in defence of the rights of people with disabilities and documentaries of living conditions for this group prepared for this development. The present study revisits two cases of the 1950s and 1960s that opened for a rethinking of architectural and residential space for frail older people and appropriate housing for young people with mobility impairments. The study uses close reading and critical analyses of textual documentation in combination with spatial analyses of drawings to retrace the awaking among Swedish architects of the need of accessibility in the built environment (Brummett 2010, Lefebvre 1985, Miles and Hubermann 1994). The study suggests that accessible architecture requires user involvement and participatory processes to conceive spatiality that is usable by people with disabilities. At the same time, consultation with people disabilities about design aspects promoting accessibility is threatened by the current Swedish housing crisis and allegations that accessibility requirements would increase building costs.

Keywords: building accessibility, inclusion people with disabilities, architectural programming

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*Speaker

Emplacing care: reflexions on housing support for persons with psychosocial disbilities in France

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The European Mental Health and Disability agendas present home care as a key tool for de-institutionalization and for the social inclusion of persons with psychosocial disabilities (Puech, 2018). In France, this political project involves actors of the Psychiatry and the Social sectors dealing with "handicap psychique" and gives rise to broad practices crossed by different fields of knowledge, professional cultures and ambitions (therapeutic, educational, political), not rarely divergent.

Thus, the practices that flow from it shape the lives of disabled persons in many ways. This paper is the result of a doctoral research in Sociology on home-based care in Paris and seeks to show how notions, such as "independent living" and "inclusion", intersect and materialize in the practices of a home-care team made up of a psychiatrist, three nurses and a psychologist.

For this purpose, the data was collected (1) from the observation, for six months, of their work and (2) from the biography and the residential trajectory of a young man who was under the care of this team. This person was met several times and interviewed during the fieldwork period. Team meetings, home visits, medical consultations, as well as the personnal experience of this person, will serve as a material for a socio-anthropological analysis of this dispositif which is set up to turn the city "habitable" (Bister, 2016) for persons with mental health issues.

Bister M., Klausner M., and Niewöhner J. (2016) The cosmopolitics of " niching ". In Urban Cosmopolitics : Agencements, Assemblies, Atmospheres, ed. Anders Blok and Ignacio Farias, 187-206. Abingdon, Oxon ; New York : Routledge.

Puech I. et Touahria-Gaillard A. (dir.) (2018) L'accompagnement du handicap à domicile : enjeux moraux, sociaux et politiques. Presses Universitaires de Grenoble, Collection Handicap, vieillissement, société.

Keywords: Home, care, psychosocial disability, moral issues, inclusion, community psychiatry

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*Speaker

From high school to higher education: exploring the transition and the academic success of students with disabilities in Italy

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Although the access to the higher education (HE) for students with disabilities (SWDs) have increased over the years, the transition from high school remains *a transition cliff*, according to Kochhar-Bryant, Bassett and Webb (2009). Support services in this stage< are still inadequate in providing helpful information to find out HE dedicated services (Newman, Madaus, Javitz, 2016; Lindsay, Cagliostro, Carafa, 2018). As a result, few students still disclose their disability; moreover, they seem more susceptible to higher drop-out rates, especially at the first year (Quinn, 2013) and they are more likely to change course of study (Childs, Finnie, Martinello, 2017). Tinto (1993) also posited that, in order to persist in college, students must integrate into formal, informal and social academic systems. Then, one of the most interesting challenges remains to look into what factors and practices lead to positive persistence in HE for SWDs.
This study was carried out in a large university in Northern Italy (Turin), that has in progress a specific project to support incoming transition called "From high school to university: supporting choice and ensuring continuity".

We address two questions in this paper. First, what are the characteristics of the academic career of SWDs (for example dropout, average scores on exams) one to three years after first enrolling and if and how they differ from those without disabilities. Second, to describe the impact di demographic/background variables (e.g. degree of disability, family background, school curriculum) and related to the in-university transition project on academic success of SWDs in these first years e to identify differences with peers without disabilities.
Analyzes are based on longitudinal data, with administrative sources, about the following three-years period after enrollment of SWDs. In order to utilize every information included in the longitudinal data, a fixed-effects models have been used (Wooldridge, 2002).

Keywords: Students with disabilities, transition, academic success, higher education, retention

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*Speaker

Some reflections on the crippled protest during the inter-war period from a transnational Europe-Americas approach

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This communication offers a first attempt of synthesis on the protests of civilian crippled persons during the interwar period. It aims to dispute the originality of the anglo-saxon protests of the 1920's and 1930's promoted by anglo-saxon historiography (Reiss, 2005 ; Reiss 2015 ; Longmore et Goldberger 2003), while trying to adopt a transnational and comparative approach between Europe and Americas. The adoption of such approach is necessary if we consider the existence of transnational advocacy networks for the rights of various categories of crippled who extend mainly to european and american countries. This research take into account all the forms of protests (street demonstration, hunger strike, work strike, walk, petitions, etc.) carried out by the blind, the tubercular and the leprous, the injured worker and other civilian crippled. Based on the analisis of several public records and digitalized newspapers available online, this research show the existence of many protests in European countries (in particular in Spain, France and England), and to a less extent in the northern and southern american countries. Most of these protests are carried out by small groups of mens (a few tens to a few hundreds of persons), moved sometimes by their communist ideology. On the two sides of the Atlantic, these groups of crippled mobilized themselves with relatively similar objectives : be cared, have a good food, obtain economic resources (pension or wage), employment, and a free education. The objectives of these protest differ according to the type of category of commited crippled persons. This communication try to analize the evolution of these protests, showing that there is much more protests during the 1930's, because of the consequences of the economic crisis on the labour market, the deterioration of the amount of the pensions, and the financial situation of the institutions.

Keywords: disability movements, Europe, Americas, protests

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[*]Speaker

Using community-based system dynamics to understand inclusion in education in rural schools of Afgahanistan and Pakistan

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Afghanistan and Pakistan are characterised by alarming education indicators: high percentage of out-of-school children, low mean years of schooling, low enrolment rates for children, particularly children with disabilities, children in remote rural areas and from poor families, girls and ethnic minorities and high rates of repetition and drop out [1-7]. Yet, efforts in education in these countries are typically geared towards increasing the overall number of schools and student enrolment, and children vulnerable to exclusion – especially those with disabilities – are either still not accessing school or, if enrolled, facing important challenges to learning [8]. The Education Equity and Quality in Afghanistan and Pakistan (EEQAP) project aims to build contextually relevant models of community-based social accountability mechanisms focusing on education of disadvantaged children – in particular children with disabilities – in 216 rural schools in Afghanistan and Pakistan. A randomisedcluster experiment has been done interviewing approximately 6,000 children, and their parents and teachers, with over 200 unique questions asked. More than one-third of these questions addressed child and parent mental and physical functioning, as well as teacher perception on disability within the classroom, and are linked to cognitive and non-cognitive learning and psychosocial skills of children. In 108 treatment schools, the intervention consists of: **(i)** training teachers and the school community on inclusive education; **(ii)** using Group Model Building (GMB) workshops from Community Based System Dynamics practice to empower local schools' stakeholders (teachers, parents, children, school committee members) to identify and draw a visual representation of the complex school system; **(iii)** having those stakeholders take the lead in identifying the issues that impede inclusion in the classroom; and **(iv)** supporting school stakeholders in defining "places to intervene" in the school system and relative mechanisms of change ("action ideas") that will be implemented with human and financial support from the three local partners.

Keywords: Inclusion, Education, Systems Dynamics, Afghanistan, Pakistan

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*Speaker

" To count " or " not to count " ? What employees with disabilities have to say about their positioning on the employment quota policy in France.

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This qualitative study in progress concerns the issues and questionings of employees with disabilities about the employment quota policy in France. Steaming from the 1987 Act of " obligation to hire disabled workers ", it imposes an employment rate of 6% of disabled workers on companies with more than 20 employees (Blanc, 2009). The Recognition of the Quality of Disabled Worker (RQTH in french) is at the center of this quota policy (Bertrand, 2017), because people with this administrative category are those that "count" as beneficiaries of the obligation of employment of companies. While the fact of having the RQTH is useful in practical terms, the decision to request this administrative category is difficult for some employees because of their fear of the possible adverse effects that may result.

Field observations and semi-structured interviews are conducted with two groups of employees of a company under disability agreement : a group that recently requested the RQTH ; and another who did not want to renew the request. The methodology used for storytelling analysis is the grounded theory where " data is systematically collected and analyzed through the research process " (page 30, Strauss & Corbin, 2005). All the data from observations and interviews generates theory, that is therefore ungrounded in the data.

The first results show that the employees evoke an ambivalent position in response to the RQTH's request, which reveals the vagaries of the disabled worker category and the ambiguity of the notion of disability situation in the context of employment. However, the decision not to renew is often adopted as a mean of claiming their professional identity, seeking recognition from the company (Renaud, 2004), or as a remedy to terminate a period of social suffering resulting from stigmatization.

Keywords: Disability, employment, work, employees, quota policy, RQTH, recognition, stigmatization.

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[*]Speaker

Anti-fascist politics of history and images of disability in GDR daily newspapers 1946-1961

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When the first issue of the SED-Newspaper "Neues Deutschland" was published on April 23th 1946, its front page was filled by a large lead article titled "Manifest for the German people". It explained "millions of dead and cripples" in Germany as the "legacy of the Hitlers, Görings, Goebbels and Himmlers" and the "quarrel between the parties". With this article, the SED connected its narrative of the immediate national socialist past with war-related disabilities and, by doing so, constructed a central aspect in its own party concept as an anti-fascist, socialist unity party. This presentation tracks the development of such narratives and searches for connected discourse changes and continuities in politics of memory and images of disability in the period between 1946 and 1961. These processes are researched by using discourse-analytical approaches on three GDR daily newspapers (Neues Deutschland, Neue Zeit, Berliner Zeitung). While research on politics of memory in the GDR found that the variety of themes was more complex than expected in a system of "steered antifascism" (Graf 2016), this complexity is denied in research on war-related disabilities. The topic was called a medially produced taboo, intentionally set up to prevent a more favorable treatment of "war-invalid" Germans to regular "invalids" (Wiethoff 2017).

By analysing daily newspapers, this presentation deconstructs the taboo-narrative. Rent-based special treatment for german soldiers, who were disabled while fighting for national socialism, touched the core of the anti-fascist self-representation of the east-german state. But instead of just not addressing the issue, the press discussed the topic with a wide array of opinions, even with reader contributions. This presentation will reconstruct this and other paradigmatic cases such as the Dresden euthanasia trial and show their importance for the east german media discourse on disability and its coping with the national-socialist past.

Keywords: caesuras and long term developments of European disability histories, international comparisons of European disability histories, media discourses, self representations, transsystemic comparisons, Disability and time experiences

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*Speaker

Changing gender relations in care for dependent elders? France 2008 – 2015

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It is commonly admitted that dependent elders are more often taken care of by female than by male informal care-givers. Male spouses and sons are less often involved in the care of elder family members, especially in hands-on care, and when they are, they do so over shorter periods and give less hours of care than female spouses and daughters. It is also admitted that in the nearby future many more informal male care-givers will be needed due to life expectancy trends of partnerships and the increase of dependent elders without female offspring. These trends are already on their way.

Our research measures male involvement trends in informal (family) care for elders, between 2008 and 2015, using two major French health and care surveys (*Handicap-Santé*, INSEE 2008; *Capacités, Aides et REssources des seniors*, DREES 2015). The surveys use similar indicators for incapacities and care, enabling detailed comparisons at seven years of distance.

Results show that the male-female gap remained important, though it narrowed over the 2008-2015 period. They also show, paradoxically, that male family members, when exposed to the need for care, respond almost as frequently as female family members. The gap in care practices, then, is more explained by different exposures to the need for care than by differences in willingness. The remaining differences will be related to socioeconomic, geographic and cultural characteristics.

Keywords: care, gender, dependency, elder

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[*]Speaker

Ableism in and beyond the Law: The Frankfurter (Behinderten-)Urteil between Disability and Legal Studies

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This paper probes the relationship between disability, the law, and ableism by examining the *Frankfurter (Behinderten-)Urteil* as a legal narrative of exclusion. The *Urteil* is regarded as a key moment in the early German disability rights movement; it led to widespread demonstrations against the systemic exclusion of disabled people after a group of disabled people the plaintiff had encountered on her vacation led to her getting reimbursed for her holiday trip ("ein unhaltbares Urteil" 1980 [2012]). I argue that as a legal narrative of exclusion, the *Urteil* produces ableism on two different levels that both inform an understanding of disability as profoundly marginalized. On the level of society, the decision reproduces the ableist image of disability as impairment so profound that it should not be visible in public. On the level of the law, the court decision reinforces this notion with a rhetoric that imagines impairment as the "profound other" and uses legal rules to establish this image as a legal norm. To understand how these forms of ableism intersect, I will analyze the rhetorics of the case and its interpretation in the German disability rights movement with a method that combines the social model of disability with the "law as narrative" approach in legal studies. Ultimately, my paper calls for the intersection between disability and legal studies to understand ableism as historically, societally, and legally specific.

Keywords: Disability law, disability legal studies, ableism, social model of disability, disability rights

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[*]Speaker

An evaluation of inclusive education in France. Survey data and first results

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Issue : With regard to schooling, the 2005 French disability policy gives every student the right to be schooled in an establishment close to his or her home and to benefit from a continuous and adapted educational path. In fact, it allows a diversity of schooling forms: reguler classes with or without an assistant, special classes in regular schools, specialized schools, schooling shared between several places. The whole device involves a large number of institutions and actors whose interests are sometimes difficult to reconcile, required to cooperate and negotiate solutions.
The presentation provides an overview of the current situation of schooling for students with disabilities in France and opens up avenues for evaluating the policy and the device for its implementation.

Data: It is based on data from three surveys: a panel, representative of the students included in the device, of 12736 disabled students, conducted by the Ministry of National Education, and two surveys conducted by EHESS, to which 5035 families and 6663 teachers from the panel responded. Data matching makes it possible to have the educational trajectory of students, the perspective of teachers and families.

Analysis : A logistic regression model was applied to some variables: nature of disability, gender, mother's diploma, child's living conditions.
Results: The stated desire for an inclusive approach open to all differences is hampered by the determination of the types of disorders on the form of schooling: ordinary classes are mainly attended by students whose disorders are not very stigmatising, while special classes and institutions include students with cognitive or psychic disorders. Social inequalities are also present: the chances of being in regular class increase with the mother's level of education. It exists significant interactions between the social capital of families, the nature of the student's disability and his or her schooling.

Keywords: Inclusive Education, National Survey, France

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*Speaker

Disability and Equality in Political Participation

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The conference contribution will deal with disability policy/politics in theory and practice. On the basis of a country comparison between South Africa and Germany and in the form of a literature review, the paper aims at investigating the enabling or disabling potential of disability policy/politics when it comes to the political participation of persons with disabilities. Having ratified the Convention on the Rights of Persons with Disabilities, South Africa as well as Germany have to implement article 29 and guarantee persons with disabilities equal political rights. Questions to be raised include the following: Which potential opportunities do persons with disabilities have in order to participate politically in both countries? What is needed to set the ground for effective political participation and self-representation, and which factors hinder their equal political contribution? Which role do the alignment and contents of national disability politics and policy play, and how are they embedded in other political activities and policy areas? First of all, the paper will discuss the terms "disability policy/politics" on the basis of existing literature and definitions, and contextualize them with other policy areas that also address disability issues to a greater or lesser extent. Then, my paper will trace the roots of disability policy/politics in South Africa and Germany. Both countries comprise of a vivid Disability Rights Movement, and both are interesting examples when it comes to questions of rights and policies due to their particular histories. The focus on concrete disability policy/ies also involves taking a closer look at participation opportunities in practice, alongside with questions of actual representation and self-representation in the political sphere. Amartya Sen's "Capability Approach" will serve as a theoretical framework to look at both prerequisites for and barriers towards political participation by focusing on opportunities and chances that are opened up through disability policy/politics.

Keywords: Disability Policy, Political Participation

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*Speaker

French Disability policies wrestling with personalization (2005-2014)

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" We dreamed of disability policies nudging towards a new relationship between the public administration and the citizen ".

This excerpt from an interview with one of the maker of the French law on disability of 2005 illustrate how ambitious the times were. With a legal definition of disability, the implementation of new local agency to implement the law, new funding and benefits and the emphasis on the "life-project" of the recipients, not only the frame of the disability policies was dramatically renewed, but the relationship with the applicants would become more personal.

As we want to show in this communication, this ambition met with a few difficulties, having to cope with difficult questions :

How to answer personally to hundreds of thousands of applications?

How to be both personalized and fair ?

Should one attribute a disability benefit on the base of a vague written life-project or should one ask for a clear and voluntary application for a given benefit?

How guided or unconstrained should be the expression of a life project in an administrative form?

We will focus on the elaboration of the applications forms and the relationship they foresee between the applicants and the administration and the place of the life-project in this elaboration. We will also give an insight of the functioning of local agencies and their actual relationship to applicants.

This communication is based on a research on the elaboration of the French law of 2005 and its implementation in two French provincies, made between 2010 and 2014. With Vincent Caradec and Jean-Sébastien Eideliman we made 40 observations in local agencies, interviewed 38 applicants to a disabled worker status, 15 professionals and 23 policy-makers and low-key civil servants in central administrations.

Keywords: Frecnh Disdability policies, Life, project, Policy Tools, Personalization

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*Speaker

Disability Data and the UN Sustainable Development Goal 4

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The United Nations have played a key role in international globalization processes because of their permanent activities to promote and monitor socio-economic developments in its 193 member-states. The latest contribution to these practices was made by the adoption of the Sustainable Development Goals. Coming into force in 2016, the SDGs are a global development agenda to promote and sustain ecological, economic and social changes by 2030. For the field of education, SDG 4 requires countries worldwide to "ensure inclusive and equitable quality education and promote lifelong learning opportunities for all". Following the slogan of "leaving no one behind", the focus in the implementation of SDG4 is on those groups most vulnerable to exclusion and marginalisation, such as persons with disabilities. Disability has thus a crucial factor to be acknowledged and considered in any efforts to monitor the realisation of SDG 4. But what does it actually mean to disaggregate data by disability in order to measure the progress of countries in achieving the goal of inclusive education? To answer this question, we focus in this paper on the relation between disability and educational progress conceptualised within the framework of SDG4. We first trace the historical processes that paved the way for disability to become a crucial (statistical) factor used to measure countries' achievements in realising global development goals; and secondly, we elucidate the impact this disability data has on the medicalisation of social phenomena such as educational change. We will argue that the attempt to overcome the vast exclusion of persons with disabilities from education through their inclusion into data has a paradoxical effect: even though it strengthens their recognition as holders of the right to education, this does occur at the expense of restricting the social model of disability that provides the base for SDG4.

Keywords: disability data, SDG4, Washington Group Questions, medicalisation

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*Speaker

Special Education Classification and the UNCRPD: Legitimizing Segregative Structures

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With this paper, we would like to discuss the significance of classification systems for the development of inclusive education systems as demanded by the UNCRPD: What knowledge about disability is generated in special education classification systems and how do educational administration use those classifications in the process of developing inclusive structures? To answer this questions, we will combine insights from two studies. The first study compares the Nigerian and German systems of special education classifications in order to analyse their significance for the realisation of the human right to education (Biermann & Pfahl, 2018). Taking a perspective of sociology of knowledge, it shows what knowledge about disability both classification systems generate and to what extent this knowledge contributes to the inclusion of pupils into local schools in their communities. Moving from the international to the national level, the second study compares the process of developing inclusive structures in two federal states in Germany by reconstructing the governance regimes (Gasterstädt i.V.). This project uses the Situational Analysis to focus on the complexities regarding the process of developing inclusive structures.

Discussing the insights of both studies, we will point out that classification systems are used to legitimize the development or preservation of segregated education structures around the globe thus contributing to what Tomlinson (2012) termed "the irresistible rise of the SEN industry" not instead but because of the CRPD.

Keywords: Classification, Education System, Segregation, UNCRPD, Sociology of Knowledge

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Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring

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The UN Convention on the Rights of Persons with Disabilities (CRPD) opens up new spaces between the government, the human rights system and civil society to involve the organisations of persons with disabilities in law and policy-making and in monitoring its implementation. The paper discusses the challenges for the disability movement in calling for a new politics of disability to successfully implement the CRPD and achieve full participation.

The research is based on a socio-legal approach and synthesizes key elements from the social model of disability and the disability rights movement. The theories of Habermas and Fraser on considering dialogic/participatory in the discussion of new social movements were influential in developing the research plan and the empirical data collection was carried out in the spirit of participatory research. Arnstein's ladder typology on citizen's participation gave the theoretical basis to categorize and distinguish different forms of civic participation.

The disability movement is facing difficulties in representing the different interest and needs of persons with different impairments. The research turns the attention to the situation of the most marginalized parts of the disability movement. A set of criteria on the meaningful participation of persons with disabilities is developed on the basis of the case studies in Zambia and New Zealand. This list of criteria contributes to academic knowledge during the assessment of the participatory provisions of the CRPD.

The paper describes the conditions and criteria of the meaningful participation of persons with disabilities and their representative organisations. It builds on some promising, grass-roots practices to demonstrate the complexity of shifting from tokenism towards effective involvement of persons with disabilities. Finally, it offers a list of recommendations to different stakeholders on what is needed to ensure meaningful collaboration in implementing and monitoring the CRPD.

Keywords: UN CRPD, disability movement, participation, advocacy, Europe, Global South, Africa

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*Speaker

Participatory and comparative research in the field of physical and multiple disabilities – insights into a current research project

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This research project, part of a National Research Project, aims to reappraise the experiences made by people who have been socialized in institutions for children and young people with physical disabilities. Such institutions usually unite all measures of education and rehabilitation in one place. In those relatively closed systems, the crossing of personal boundaries can occur. People affected by physical and multiple disabilities report experiencing supportive as well as coercive practices and even trauma in the context of welfare.

The project does not only aim to reappraise those conflicting practices from the perspective of the people affected, but also to use their experiences in order to gain insight into practices that foster the self-determination and recognition (*Anerkennung*) of people with physical and multiple disabilities, especially with regard to the implementation of the UN CRPD. We will conduct narrative interviews with people, born between 1945 and 1995, who were socialized in such institutions, enabling us to gain insights into the historical development of medical and psycho-social measures in the second half of the 20th century.

The project is designed to be participatory throughout: The research plan was constructed with affected co-researchers who are also being consulted for every important further step. They are integrated into the transdisciplinary makeup of the research team with the academic researchers from the fields of special education and history. The study is also comparative, as experiences from the French- and German-speaking parts of Switzerland are compared.
We will discuss methodological challenges considering participatory and comparative research and present out initial experiences with it.

Keywords: participatory research, comparative perspective, history, physicle and multiple disabilities

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Self-determination: voices of young adults with disability

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To encourage adults with intellectual disability to take control of their lives policies and decisions cannot ignore their real experiences and needs (Barton, 2009, 2005) this is present on the Convention on the Rights of Persons with Disabilities which "enshrines the notion that there should be 'nothing about us without us'" (Harpur, 2012: 2). The authors draw on qualitative research in the South of Portugal that collected the testimonies of young adults with disabilities to understand their perceptions and experiences about their social inclusion, with emphasis on school education, professional integration and leisure activities. These testimonies are given in the first person and not by families or professionals (MacDonald, Kidney & Patka, 2013; Mitchell & Sloper, 2011). The study followed a qualitative approach, using individual semi-structured interviews to young adults with disabilities (trisomy 21 and cognitive deficit). The results showed that (a) Professional experiences little positive: "we work but we don't get money";(b) Internalized space recognition of the family as a single personal experience; (c) Participation in decisions about your life: little or no references; (d)The leisure space as privileged space of positive reinforcement: feel busy/feel useful; To be able to do something; find friends; (e) The family as a privileged space for personal experience and welfare/happiness; (f) The need to develop in young people with intellectual disabilities skills that enable to autonomy and self-determination.

Keywords: Self, determination, Inclusion, Young people with disabilities.

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Educational policy and school practices: Fighting for inclusion education

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Despite the educational policies for inclusion education of students with special needs, in particular with *intellectual development* disorder or autism spectrum disorders, the practices in portuguese schools are integrating more than inclusion. In order to counter these practices and to achieve a real educative inclusion was published in July 2018 Decree-law nº 54/2018 about Inclusive Education. This communication presents the results of a study, still ongoing, which aims: a) understand how schools and teachers are applying the new legislation; b) identify factors that hinder/ limit or facilitate the educative inclusion; c) to know if the integration oriented practices have been replaced by inclusive practices within the school. The study takes a qualitative approach and focuses on the testimonies of teachers of basic education (1º, 2º e 3º cycle) who teach in schools in the southern region of Portugal.

Keywords: Keywords: Educacional policies, Inclusive education.

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*Speaker

Disability and occupational inequalities in France: a quantitative and sequential approach

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While a strong correlation between disability and employment outcomes has been documented (OMS & Banque Mondiale, 2011), some mechanisms of this relationship are still to be explored. The professional disadvantage may preexist or follow the onset of disability (Jenkins, 1991) ; in the second case, when and how do these inequalities develop ? How do social forces and individual attributes interplay in such processes ? (Shakespeare, 2013)

In accordance with a life-course approach (Priestley, 2003), this quantitative study makes use of the wave 2011 of the French Labour Survey ("*Enquête Emploi*") and of its additional module to quantify (pre-)professional inequalities faced by people who grew up with various types and degrees of impairments and limitations, at different sequences: diploma, employment rate (among working-age population), unemployment rate (among people actively looking for a job), job position (for employed people), labor income (for employed people).

Through descriptive statistics and logistic regressions, it appears that disadvantages emerge earlier for people with cognitive limitations (through low education level and low employment rate) but that they further deepen for people with visual or motricity limitations when entering the job market. The situations of people with psychological illnesses or chronic diseases locate between these two extremes. The level of disadvantage is proportionally weaker for people with hearing or moderate limitations. Social influences such as meritocracy, inaccessibility, and discrimination, may feed these processes.

Keywords: interactional model, type of limitation, type of impairment, degree of limitation, education level, employment, job position, labor income

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*Speaker

Employer responses to recruitment of persons with mobility impairments on the Danish labour market

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Employers are crucial in determining the labour market position of persons with disabilities by deciding how to post vacancies, whom to invite for interviews, how to select among potential candidates, which candidates to recruit and which work and wage conditions to offer employees. Despite the societal importance of these corporate decisions, we know surprisingly little about how and why companies make different decisions regarding persons with disabilities. In this study, we examine the attitudes and behaviour of employers towards persons with mobility impairments in Denmark. In a comparative perspective, the Danish labour market is renowned for "flexicurity" by combining high labour market flexibility with social security and active labour market policies. Danish flexicurity implies that companies are not obliged to recruit disadvantaged jobseekers like persons with disabilities, as long as they do not violate anti-discrimination laws. We, therefore, expect to find major variations between Danish employers and examine these differences in employer responses by using a new typology that differentiate between employer attitudes and behaviour. We identify four types of employers: The committed employer (positive attitudes and positive behaviour), the dismissive employer (negative attitudes and ngeative behaviour), the sceptical employer (negative attitudes and positive behaviour) and the passive employer (positive attitudes and negative behaviour). By using data from a national representative survey of Danish employers, we find that the majority of Danish employers are "passive" (54%). The remainning employers are either "committed" (22%), "dismissive" (20%) or "sceptical" (4%). We examine the characteristics of the different types of employers, and contribute to the literature by increasing our understanding of the variations in employer responses to recruitment of persons with disabilities.

Keywords: Disability, employment, employer, recruitment, Denmark

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Court-Appointed Legal Representatives / Betreuer in Germany: Quality Requirements and their Implementation Regarding art. 12 CRPD

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In 2015, the Federal Ministry of Justice and Consumer Protection commissioned a research project, also with regard to the CRPD Committee's criticism concerning Art. 12 **CRPD** (2015) and the German Law of Betreuung. The research project was concerned with questions of how the Law of Betreuung is implemented; what the guiding principles for quality standards are; whether structural quality deficits exist, and if so, what the possible causes for these deficits are. The study is based on a concept of quality which was empirically verified. The concept states that a good management of Betreuung is guided by the basic principles stemming from German Basic Law, CRPD, and the regulations for Betreuung in the German Civil Code. Basic principles of court appointed legal Betreuung can be derived from these, they include: The self-determination of the person concerned must be ensured. At the same time, the person must be protected against significant harm, undue influence, exploitation, and external determination. The individual *and subjective* welfare /(best interpretation of) will and preferences of the person is the crucial aim of Betreuung. One of the key principles is the principle of necessity. Support is given as personal *Betreuung* with the obligation to discuss important matters with the person before taking action, also to hear his/her wishes and to be able to assess their subjective welfare.

With this in mind, the talk will focus on research outcomes regarding service users involvement, necessary knowledge; social competencies; further education activities; the procedure in supported decision-making; and how to deal with conflicts. Moreover, the perspectives of persons concerned will also be presented.
The report: https://www.bmjv.de/SharedDocs/Downloads/DE/Service/Fachpublikationen/Forschungsbericht

Keywords: UN CRPD

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*Speaker

Sex Damages: The (mis)conceptions of (dis)ability and sexuality in Israeli tort law

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This paper interrogates the sociolegal construction of disability and sexuality in personal injury court decisions over a 25 years period. The paper introduces the notion of sex damages and examines what remedial avenues have been and could have been developed to compensate for harm to sexual functioning following an injurious event. We offer a normative framework for disability and sexuality, one that relies on a human right to sexuality of disabled persons and the political idea of *disability sexual citizenship*. We conducted an empirical analysis, using mixed quantitative and qualitative methods to examine the changing forms and patterns of sex damages in Israeli district court decisions. Our major findings were that courts do not often address matters regarding harm to plaintiff's sexuality. When they do, they usually employ narrow and conservative views and tend to compensate young males who experienced substantial harm to basic male sexual functioning with a focus on penetration and procreation. However, when places on a timeline, a gradual shift occurred towards more progressive remedies and more inclusive decisions in terms of plaintiffs' gender and age. Interestingly, since 2010 there was a sharp decline in total number of such rulings. The paper discusses these shifting trends and concluds with a call for an affirmative view of disability and sexuality, one that includes all persons with all types of impairments, that emphasizes the social barriers that disabled people face when wishing to express their sexuality, and supports disability sexual citizenship.

Keywords: Law, Sexuality, Mix Method, Citizenship, Sexual Rights

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Telling Disability Stories: Legacies, Imagination, Coalitions

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Disability historians play a critical role in telling and retelling stories of the past. Centering on the lived experiences of disabled people, this keynote raises questions that reflect the complex, messy process of recalling the past and of repopulating it. Disability scholars must grapple with the intimacy and vulnerability of forced institutionalizations and other violent medical interventions, of daily life, of community formations, and of activism-to name just a few themes in global disability history. For many reasons, the stories told by asylum administrators, medical professionals, and policymakers often shout louder than the versions disabled people might tell. This encourages many disability historians, then, to seek and tell disability histories, reinterpreting traditional sources and accounts, and using new and different primary sources. The disability historian's work in retrieving disability stories may stir questions of privacy and shame, but may also preserve the everyday acts of solidarity and creativity that continue to inform disability cultures. Examples of this abound, from emerging oral history projects and asylum cemetery reclamation efforts, to creating accessible archives and addressing racism and homophobia in our disability rights campaigns. Our work in global disability history ultimately may restructure knowledge itself–in form, content, and interpretation.

Keywords: Disability History

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Bringing Sunshine Children into the Light: Experiences of mothers of children with Down Syndrome in Kyrgyzstan

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Issue Addressed: Very little research exists describing experiences of individuals with disabilities in post-Soviet Central Asia. A Soviet legacy of stigma and discrimination has led to marginalization of children with disabilities in Kyrgyzstan, one of the poorest countries in Central Asia. Down Syndrome (DS) is a particularly stigmatized diagnosis and mothers are often blamed for bearing an "invalid" child. Partnering with Sunterra, an organization for parents of children with DS in Bishkek, Kyrgyzstan, researchers aimed to describe the social environment and qualitative experiences of mothers of children with DS.

Data: Qualitative interviews were conducted with 7 mothers of children with DS and 5 professionals who work with children with disabilities in Bishkek, Kyrgyzstan and were analysed for themes using Bronfenbrenner's Ecological Systems Model.

Analysis: Qualitative analysis yielded themes illuminating layers of a defect-focused environment, the need for mothers to redefine their identity in light of stigmatising narratives, and the power of collective capability found in community with other mothers of children with DS.

Results: Defect focused attitudes toward DS in Kyrgyzstan constitute an environmental barrier that isolates mothers and their children with DS. To battle negative attitudes, mothers have redefined their identity and valorised their children with DS. Together, mothers are self-mobilising and exploring forms of activism for their children. More research is needed to clarify how rehabilitation professionals can further empower this population.

Keywords: Down Syndrome, children, Central Asia, Kyrgyzstan, mothers, disability, defectology

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The Role of the Human Rights for the Normative Entitlement of Inclusion in Modern Society

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Although there seems to be a general consensus that every person should be part of the society, Inclusion is discussed controversial. To understand that contradiction and find well-founded arguments against practices of exclusion, this lecture takes a descriptive analysis about how human rights and the foundation of the functional differentated society are related to each other and why this leads to an entitlement of inclusion.

Luhmann (1965) showed, that human rights and the foundation of the functional differentated society are directly related. In accordance with Lindemann (2009) the normative aspect of the human rights has to be added by a cognitive aspect - the biologically alive human - which she argues to be the border regime of modernity". These two aspects combined create the institutional complex human being / human rights'. This institutional complex logically implies an entitlement of equal participation of all biologically alive humans as persons in the society, which we generally call inclusion. Because of that every kind of exclusion in the modern society cannot be accepted on principal and has to be justified very well.

However, empirically people with disabilities are excluded very often. One way of explaining that contradiction can be done with Stichweh's (2016) theory of inclusion/exclusion as a hierarchally opposition: To fulfill the entitlement of inclusion, every kind of exclusion in modern society has to be put in form of inclusion. That is exactly what separating practices against people with disabilities are about, with the effect, that the exclusive moment of the practices is masked as efforts of inclusion.

Keywords: Inclusion, Human Rights, Modern Society, Functional Differentation, Exclusion

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[*]Speaker

Representations of Disabled Women in Malta

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Being a woman and being disabled is often associated with a higher risk of experiencing discrimination than disabled men and non-disabled men or women (Pinto, 2013). The study of social representations of disabled women can aid in improving disabled women's wellbeing and in securing their independence and autonomy (Council of Europe, 2003). In this study, the representations of disabled women were investigated. This paper reports the findings of a survey carried out in Malta in 2016 with a random sample of 526 participants. Perceptions of disabled women were investigated using 12 Likert scale statements and an open ended question. The topics covered by the statements were employment, education, relationships and motherhood. Results were analysed using SPSS. The adjectives given by the participants in the open-ended question were analysed using Multi-Correspondence Analysis (MCA).

The results of the survey show that younger people (16-29 age group) have more positive representations of disabled women than those forming part of the 30-49 age group. They believe that disabled women are good students and employees. No gender differences were found.

The results of MCA showed that those participants who were over 65 years old tended to perceive disabled women as 'less fortunate' and 'pitiable'. The participants belonging to the 16-29 age group used adjectives emanating from a perception of disability ingrained in a rights based perspective such as 'equal', 'determined' and 'disadvantaged'. Whilst those participants belonging to the 30-49 and 50-64 age group tended to perceive 'disabled women' as 'courageous' and 'intelligent' whilst at the same time as 'fragile' and 'unlucky'. Implications of these findings will be discussed in the light of how representations can be changed in order to increase disabled women's participation and social integration in the community.

Keywords: gender, disability, intersectionality, disabled women, social representations

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*Speaker

People with disabilities in Southern Europe and the welfare state: exploring longitudinal patterns in political attitudes and subjective well-being

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Southern European countries share some features regarding their welfare regimes (Castles & Ferrera, 1996; Ferrera, 1996) that may influence subjective well-being and political attitudes. While persons with disabilities report, on average, lower levels of "subjective well-being" than persons without disabilities, this gap is less pronounced in Nordic countries, than in Eastern European countries . Among Southern Europe - Portugal, Spain, France and Italy research further shows that Portugal is the country where the disparities in this indicator are wider (van Campen & van Santvoort, 2013).

Drawing from European Social Survey data, a biennial cross-national survey of values and social and political attitudes in Europe since 2002, and from other secondary sources of cross-national data on European countries, this presentation aims to:

1) Deepen our knowledge on the situation of persons with disabilities in Southern Europe, regarding indicators connected to "political attitudes", "subjective well-being" and other relevant data, exploring differences and similarities between countries;

2) Assess longitudinal trends, within and across Southern European countries, paying special attention to the role of the recent economic crisis on possible changes across these indicators. Relying on these analyses, some explanatory factors for the inequalities encountered will be discussed.

Keywords: Disability, Southern Europe, welfare regimes, subjective well, being, political attitudes, indicators.

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Child mental disabilities, care-givers burden and its implications on Global Migration: a case study of Kiambu County, Kenya

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Background; In Kenya, children with intellectual disabilities (Down syndrome and cerebral palsy) as well as learning disorders (Autism spectrum disorder, dyslexia and epilepsy) are all collectively termed as mental disabilities (MD). Such children face varying levels of discrimination in different facets of life. This paper will be a summary of the findings of research work conducted partially in Kiambu and Nairobi Counties in Kenya. *Method;* I chose a mixed methods approach to conduct the research through the Kenya Institute of Special Education (KISE) situated in Kasarani constituency in Nairobi County, Kenya in 2018 for a total of three months. 90 questionnaires were filled out by parents whose children suffer from a form of mental disability (aforementioned). 15 key inormant interviews were conducted with experts on Disability and education, non-governmental organizations and health practitioners from several hospitals. Five focus group discussions (3 with parents of low social economic status while 2 with parents from high economic status). *Results;* Using the conceptual model of Care-givers burden or caregivers strain, the researchers were able to understand the burden of care for such children.Capability and functioning of such children ranges between; mild, moderate and severe. This creates a structural stratification in the way the community, health services and educational institutions assist such children. This may affect the mobility choices by parents or guardians of such children. The choice to migrate is both domestic (from rural to urban areas) as well as international (from a less developed country to a developed country) and is motivated by uncertainty about the education options as well as social exclusion of their children in the society. The choices and reasons given to migrate are constantly changing. *Conclusions;* There needs to be social transformation inorder to achieve inclusion from community members and service providers in less developed countries (Global South).

Keywords: Migration, intellectual disability, children, inclusive education, care, giving burden

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[*]Speaker

To reveal or conceal? Construction of a self-reflection aid for employees with invisible disabilities.

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Background

Most employees with invisible disabilities are at some point confronted with the decision of whether, when and how to communicate their condition at work. As (non-)disclosure can lead to a variety of consequences that can either foster or counteract quality of life and workability, the considerations might become overwhelming [1, 2]. Thus, the aim of our project is to construct a self-reflection aid that facilitates an informed decision. The objective of the first project phase is to determine its format, structure and contents.

Methods

An analysis of theoretical frameworks and existing research was combined with data collection via expert surveys (e.g. company doctors, self-help organisations, employers) and a quantitative online survey ($N = 274$ employees with chronic health conditions).

Findings

Existing research and our own data reveal the complexity and individuality of the disclosure decision. To offer individual and low threshold support, an interactive online tool appears to be the appropriate format. In line with motivational theories, the self-reflection aid will have a tripartite structure addressing anticipated positive and negative consequences, the likelihood in which these might occur and ways to cope with them. The self-reflection aid will focus on individual and organisational factors (e.g. organisational climate, stigma) that have proven to be connected to decision outcomes.

Discussion

The planned decision aid aims at supporting individually good decisions that might in turn foster desirable work outcomes and quality of life. Besides its practical relevance, it allows for new empirical insights, as research on this topic is scarce.

Keywords: self, reflection aid, disclosure decision, chronic health condition, work inclusion, quality of life, workability

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Disability and Employment in Mozambique: Results of an Emancipatory Disability Research

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The paper will propose an analysis of the barriers preventing young persons with disabilities living in Mozambique to have access to a decent job. The paper will analyse both persons with disabilities and employers perspectives by using quantitative and qualitative data collected by Mozambican persons with disabilities who participated to an emancipatory research experience.

Emancipatory research finds its roots in Paulo Freire work in Brazilian slums: one of the point raised by Freire is that the poors, the excluded and the marginalized have sharp analitical skills when they have the chance to put them in practice. Moreover, persons belonging to marginalized group should get control over the process of knowledge production about themselves, their problems and the context they live in as part of a process of emancipation. Starting from the 90' (Barnes, 2014), Emancipatory Research has been applied in the field of disabilities studies.

From a a practical point of view, in the case of the experience presented in this paper, a group of young persons with disabilities has been trained about how to develop a research protocol (i.e. developping methodology, designing research tools, identifying a reserch question...). They have been involved in the elaboration of a "true" reserch project and they have been in charge of data collection and data analysis (thanks also to the support provided by their DPO, international NGO, the researchers of the University of Florence and of the Mozambican Statistical Institute). The research included two surveys: the first addressed to young persons with disabilities involved in vocational training and the second involved employers. The result was a picture of the barriers (facilitators) hampering (favoring) the participation of young Mozambicans with disabilities to the job market. The quantitative results were complemented by qualitative data through Focus Group Discussions and key informant interviews

Keywords: Disability Data, Emancipatory Research

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*Speaker

Intellectual disabilities and local welfare systems: policy practices and a field research in a provincial district in Northern Italy

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The paper aims at presenting the results of a research on intellectual disability in a provincial district in Northern Italy; moreover, it explores the relationship between field research and policy/organisational practices in the field of intellectual disability.

Public and private social and health services, several voluntary associations, persons with disabilities and their families composed the research group. The group was coordinated by two researchers and aimed to highlight strengths and weaknesses of the local welfare system and to promote a redefinition of policies and interventions in the field of intellectual disability at the community level. The research has been limited to three areas considered as meaningful dimensions of independent living in adulthood: work, quality of life and housing. The literature on these areas was reviewed (e.g.: Angeloni 2013; Schalock, Bonham and Verdugo 2008; Marchisio and Curto 2013) and both international and Italian legislation was investigated. Quantitative and qualitative analysis in the three fields of research was carried on throughout four focus groups and fifteen key informant interviews. The analysis allowed to point out four peculiar features of the local welfare system: coexistence of different housing opportunities; role of free time activities; need of better coordination between job placement services; need for changes in day-time residential services. Furthermore, these results were discussed with ten persons with disabilities and/or their families.

Thanks to the interviews and the continuous dialogue with local stakeholders and users, the researchers were able to point out convergences, overlaps and the areas where fine-tuning is needed. As a conclusive result of the project, a Protocol was subscribed in order to coordinate actions and resources towards a more appropriate answer to the needs of persons with intellectual disability. Moreover, the research group - involving both service providers and users - was established as a permanent community of practice.

Keywords: intellectual disability, field research, Italy, local welfare system, independent living, community of practice

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"Disability and (new?) Possibilities for Political Participation in Regions"

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Diversity and resulting constructions of identity are increasingly incorporated into political processes, both by individuals claiming their human rights and by collective actors joining forces to reach common goals. Possibilities for political participation are therefore a necessary prerequisite for the representation of different groups characterized by diversity (e.g. national minorities, migrants, persons with disabilities) in policy-making processes and are also outlined by international human rights standards (e.g. Article 29 UN-CRPD). In the European multi-level-governance system, this implies a responsibility and obligation to improve the inclusion of persons with disabilities in political processes for the EU as well as for national and sub-national decision-makers. Participation thresholds are lower on the local and regional than on the national and supranational levels, facilitating the inclusion of citizens into policy-making processes; the EU's principle of subsidiarity also promotes regional decision-making. New forms of political participation (e.g. online platforms, open spaces for citizen discussion) may render participating easier and less costly and resource consuming for persons with disabilities, and may thus also impact their willingness to engage in political processes and their possibilities for collective identity formation. My paper will therefore look at participation processes of persons with disabilities at the regional level, and investigate the role of diversity and identity formation in triggering political participation in traditional (elections, consultative bodies, protest movements) and new (online platforms, social media) forms. The regions of Bavaria (Germany) and South Tyrol (Italy) will serve as case studies; both regions have recently implemented inclusion laws or action plans through participatory processes, and both held regional elections in October 2018. Data will be gathered through document analysis (e.g. party and electoral programs, action plans) and by conducting qualitative structured interviews with officials, members of self-representation organizations, party members, and civil society activists.

Keywords: political participation, policy making, civil society, federalism, new media, regional level, Germany, Italy, Bavaria, South Tyrol

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War disability and "natural" disability: physical disability between embodiment, subjective perceptions and inequalities in Tigray region (Northern Ethiopia)

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This paper is the result of an anthropological research for my PhD dissertation, carried out between October 2014 and June 2015 in Tigray Region (Northern Ethiopia) focused on perceptions and management of physical disability. During the fieldwork, based on a qualitative approach characterized by participant observations and in depth interviews with different kind of informants, disability appeared as a relational product, culturally, socially and politically shaped.

Tigray Region has been involved in a long history of war, therefore the big amount of physical disability among the population is even the result of the war in a direct and indirect way.

But in the context examined the difference between war disabled - the ones that acquired disability due to their direct involvement in the war- and "natural" disabled is fundamental, both on the side of the socio - political management and on the one of the intimate and subjective perceptions of disability.

If disability is a "negative social response to a perceived impairment" (Shuttleworth - Kasnitz, 2004) I will try to highlight how the disability of the veterans has not dis-abling effects on the social actors, while the "natural" one is perceived as a "lost" and immediately associated with the topic of "vulnerable citizenship". Discourses and representations elaborated by disabled people about their physical condition, reflect the way in which society and the State look at them in an "intimate dialogue between state and citizens" (Pizza, Johannessen, 2012 [2009]: 121). The perceptions of a dis-abling disability of the natural disabled and a non-disabling disability of the veterans are the result of a process of embodiment and of a "politic of disablement" (cfr. Oliver, 1990). Through the discourses of the informants I will try to shed light on this process and on the creation of inequalities in the experience of disability.

Keywords: physical disability, embodiment, Tigray

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*Speaker

Your suffering will (not) be televised. Depicting disability in Norwegian telethons, 1981-2002

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Every autumn since 1974 Norwegians watch TV-aksjonen, the world's largest volunteering and donation show organized by public broadcaster NRK. Disability has been the centre of attention several times, most notably during the UN International Year of Disabled Persons (IYDP) 1981, where the focus for the first time was on developing countries, as well as 1991 and 2002. While American telethons were company-sponsored and tended to depict disability as a spectacle of passive suffering (Longmore 2015), the case of Norway with its welfare principles of solidarity, equality and community raises different expectations. And indeed, with neighbouring Sweden only last year collecting 5 million Euros for children with disabilities in the Global South, the popularity of telethons in the Nordic countries seems unbroken.

The media are key in (re)producing cultural values and shaping public opinion. In 1981, however, the Norwegian audience was presented with two different, even contradictory images of disability. Whereas the program Disabled?! visualized empowerment, equality and social inclusion through the lives of disabled Norwegians, the year's TV-aksjonen A New Life, though created together with disability organizations, reproduced notions about disability in developing countries not unlike American images of suffering and passivity.

This presentation analyses TV-aksjonen in 1981, 1991 and 2002 against the background of a broader historical shift: from disability as a domestic issue towards a more ambiguous global understanding. How has the portrayal of persons with disabilities changed over time, and which normative messages were connected to this change? To what extent did TV-aksjonen promote or counteract the goals of Norwegian disability policies and organisations? I argue that TV-aksjonen in its depiction of disability mirrored the aims, but also limitations of contemporary international discourses, while being crucial to shaping society's perceptions of disability as a transnational issue that became increasingly aligned with Norwegian values of self-organization and advocacy.

Keywords: caesuras and long term developments of European disability histories, international comparisons of European disability histories, media discourses, self, representations, transsystemic comparisons, Disability and time experiences

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[*]Speaker

Between vision, life story, and ordinary experience: Anthropology of Daily Life at the Little People's Kingdom in Yunnan Province, China

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The Little People's Kingdom in Yunnan Province, in P.R. China is a privately-operated Park where more than 100 people of short stature are living and working. In this paper, we explore the tensions between the vision of businessman Mr. Chen who has founded the Park with the permission of the government under a cultural industry scheme, the life stories of little people who express a history of suffering and sanctuary, and ordinary experiences as workers in the Park that cry out boredom, routine, and at best a step in professional development. We situate the Little People's Kingdom between an imaginary paradise, a sanctuary, and an industry. We also argue that theoretical concepts such as freakshow, human zoo, and state of exception are flawed, and that the phenomenon of the Little People's Kingdom can better be theorized as a momentary response in the rapid modern development that addresses tensions between progress and charity.

Keywords: little people, China

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*Speaker

Overcoming the research-practice gap; shared agenda setting for research & action on employability of persons with mental disabilities in East Africa

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Background: Overcoming the research-practice gap is a critical problem in disability studies. Shared agenda setting for research is considered the preferred start to bridge the research-practice gap. The objective of this study was to identify success factors for generating knowledge on employability of persons with mental disabilities in East Africa, not *for* but *with* potential users of this knowledge. In our contribution, we elaborate on the stepwise process, the underlying principles and on the challenges we encountered whilst conducting the research.
Methods: A mixed methods study design

Results: Preparatory phase: a preliminary actor and problem analysis based on literature and informal conversations. Phase one: understanding the problem by conducting interviews with potential knowledge users and refining earlier findings through triangulation. Phase two: shaping a shared research & action agenda, by holding FGDs to validate preliminary results. Phase three: stakeholder meeting to share and further validate the findings from all previous phases and formulate shared recommendations. Principles that appeared to be conducive to the transdisciplinary research process were: the emergent design process; involving potential knowledge users from the start; integration of all stakeholder perspectives. Challenges that were encountered included gaining the trust of persons with mental illness to tell their story and employers and policy makers to discuss the subject, and stimulating NGOs to spearhead the process.
Conclusions: As the current study follows an emergent design process, the distinction between formulating the research proposal and developing recommendations is less clear-cut and both may happen from the start, albeit in an increasingly more detailed fashion throughout the course of the research. The transdisciplinary approach to our study objective offered a bird's eye view on challenges and opportunities for improving employment for persons with mental disabilities in East Africa

Keywords: shared agenda setting, transdisciplinary research, mental disabilities, employability, East Africa

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*Speaker

A Critical Disability Studies Approach to Early Childhood 'Inclusive' Education

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The purpose of this presentation is to describe a gap persists between the fields of early childhood 'inclusive' education and Critical Disability Studies (CDS), and what a CDS approach to early childhood 'inclusion' might look like. I begin by presenting my analysis of the language used within the literature on 'high-quality inclusion' in the United States (i.e., Barton & Smith, 2015; DEC/NAEYC, 2009; Soukakou, 2012), and suggest that the policy and practice recommendations "are never as positively progressive as they claim or may seem" (Shildrik, 2012, p. 38). In other words, the field of early childhood inclusive education, despite adopting policies and practices that explicitly claim to engage in "ongoing evaluation of existing power structures, discourse, and culture" (Rausch, 2015, p. 83), fail to truly grapple with the questions a CDS approach would propose, such as: "Who is included? Who is not? Who needs to be included? Who or what decides? What is the role of the Normal" (Watson, 2016, p. 2)? Based on my analysis, I will propose a path forward, suggesting how CDS may be applied to early childhood 'inclusive' education. My proposal draws on the work of Graham and Slee (2008), who suggest, "Perhaps the question now is not so much how do we move 'towards inclusion'...but what do we do to disrupt the construction of centre from which exclusion derives" (p. 279)? In order to achieve this disruption of the centre, I suggest a CDS approach to early childhood 'inclusion' that focuses on (1) a critical history of the Normal (Foucault, 1972; Rose, 1990; Ewald, 1992), (2) the identification of ableist practices (Franck, 2018; Watson, 2018), and (3) the space for a reimagining of "dis/ability as the very condition of human becoming" (Shildrick, 2012, p. 37).

Keywords: critical disability studies, childhood, inclusive education

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[*]Speaker

Clothing Influences Participation of Persons with a Physical Disability: Results from a Scoping Review

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Background: Determining ways to facilitate meaningful societal involvement of an increasingly disabled population is crucial. Clothing can help or hinder the ability to fulfill daily needs and social roles; the act of dressing and other clothing-related activities are often challenging for persons with a physical disability (PWD). Clothing design and wearable technologies are growing industries, however, industry uptake of adapted or inclusive designs seems slow. Objective: To map the state of the knowledge about the role of clothing on participation of PWD, as reported by scientific and grey literature. Methodology: Six research databases (MEDLINE, Embase, CINAHL, ERIC, PsycINFO, Sociological Abstracts) and grey literature were searched. English or French articles between 1990 and 2018 concerning PWD aged 14+ years and contributing to how clothing affects function, activities, participation, and quality of life were included and extracted based on the International Classification of Functioning, Disability and Health (ICF). Results: Fifty-seven articles and 88 URLs were included, with 47.4% articles published after 2009. Articles highlighted the multifactorial influence of clothing on participation through the majority of ICF chapters. Frequently reported chapters include: Products & Technology, Self Care, Mobility, Attitudes, and Services, Systems & Policies. Personal Factors, although un-coded in the ICF, were also frequently reported and equally valued. Perspectives from a variety of stakeholders and PWD with diverse diagnoses were represented. Numerous companies presenting adapted products online were found, including specialized tailors and de-

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*Speaker
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signers. Discussion: A surprising breadth of knowledge was retrieved, leaving the authors with more questions than answers. Results indicate that indeed, clothing is important to facilitate the participation of PWD and a call to action for implication from numerous sectors is needed. Future research should consider the knowledge uptake among the textile/design industry.

The Reception of the UN Convention on the Rights of Persons with Disabilities: A French Perspective

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The ratification of international conventions and their effects on national policies deserve to push forward interdisciplinarity. This proposal draws on the specific case of the UN Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN General Assembly in 2006 and ratified by 175 Member States ever since.

The paper will focus on the Article 12 of the CRPD, which recognizes the equality of everyone before the law and how it is actually put in practice in a variety of countries. This article has been subject to much discussion during the drafting of the convention, its interpretation is still very controversial, especially since the publication of the General Comment n1 by the UN Committee of the rights of persons with disabilities, and the reception by State Parties is a very relevant indicator of the influence of the CRPD on national policy.

A large body of specialized literature has been devoted to the CRPD worldwide since its adoption (Arnadottir and Quinn, 2009; Sabatello and Schulze, 2014). Jurists and specialists in the disability sciences comment extensively on the signing and implementation of the Article 12 of the Convention (Degener, 2017; Freeman et al., 2015). The authors themselves have participated in the debates on the reception of the CRPD and its article 12 by organizing national and international events in Germany, UK and France (EAP, Martin et al., 2016, Brosey et al., 2018, Confcap, Eyraud et al., 2018,)

Our paper relies on our experience of the discussion about CRPD in France. We participate in the framing of the discussion about article 12, as much with people who experiment disabilities than with administrive bodies in governmental commission. We would try to show the necessity to bring different kind ok experential and expertal knowledge on the legal capacity issue.

Keywords: UN CRPD

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[*]Speaker

Brave new world of work through the lens of disability

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Work and paid employment has become a central aspect of social identity in our contemporary work societies (Beck 2001). The assumed positive aspects of wage labour and employment on individual well-being are hardly questioned. It is instead claimed that work offers the individual a sense of purposefulness, a possibility to contribute to the collective good and a daily structure. Since its late emergence in the 1960s, the disability rights movement has put an emphasis on exclusion from work and employment. Nevertheless, all over the world, people with disabilities still belong to the most marginalised groups in the labour market. Critical disability scholars thus call for a radical transformation of the ontologies of work and employment (Abberley 2002). Using disability rights monitoring as a method, this paper explores what role the disability rights framework plays in shaping and transforming our present work society (Rioux&Basser 2011). Based on a German context, it is outlined how the international human rights framework has influenced the social policies that support the inclusion of disabled people in work and employment. Including the narratives of disabled people, it is shown that despite comprehensive anti-discrimination legislation, the German labour market remains exclusionary and discriminatory against people with disabilities. Recently introduced measures, however, point to a new direction and aim to create a more equal and just world of work that acknowledges embodied differences and the needs and capabilities of disabled and non-disabled workers.

Keywords: employment and work, disability, human rights, social participation, Germany

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[*]Speaker

Cognitive accessibility of ordinary housing: the example of persons living with trisomy 21

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Although the French context functions within the framework of the CRPD, the CEH, the law of 2005, and various regulations concerning the accessibility and adaptability of the ordinary housing environment, the latter remains minimally inclusive for people with cognitive disabilities. It is therefore important to gather scientific knowledge that addresses this issue and supports the efforts of actors building a more inclusive society.

In this perspective, research was conducted between 2016 and 2018 in order to discern: specific needs in the area of housing and its adaptation to people with cognitive limitations; the different solutions envisaged/tested and those chosen; the arguments underlying the choices in habitat adaptation; the self-determination of the person directly concerned in these choices and arguments.

A field survey was conducted among two different populations: 13 people with trisomy 21, having lived in their own home for at least one year; a similar number of involved parents and support professionals. Survey techniques used included semi-directive interviews and home visits, the latter guided by their inhabitants and recorded.

Analysis based on a symbolic and pragmatist interactionist theoretical framework (Berger, Luckmann, 1996, Goffman, 1973, 1991), on support for self-determination (Wehmeyer, 1996, Lachapelle, Wehmeyer, 2003), on accompaniment (Stiker, Puig, Huet, 2014) as well as on technical documentation (CERTU, 2013; UNAPEI, 2009) yielded results concerning: 1) conditions favoring housing access in ordinary environments; 2) adaptations of the material and human environment facilitating self-determination in daily life.

Keywords: Accessibility, Housing, Cognition

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[*]Speaker

Disabled people's organisations' identity in Poland.

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Purpose: The aim of the study was to explore the roles and functions of DPO (ascribed on themselves) against the background of NGOs not-governed by persons with disabilities.
Method: The survey is based on qualitative data derived from in-depth interviews with DPO members and board members. Because of small number of DPOs in Poland the snowball sampling was applied.

Main issues: How DPOs perceive their role in polish disability movement in reference to the matter of representation. Why organisations want to be a DPO? How they become DPO? What aims they have? What disability paradigms they approve? What obstacles they encounter? Is being DPO a value for its members?

Results: The survey reveal a dilemma between being an advocacy activist and a service provider. It also shows conflict regarding disability movement representation among disability related organisations as well as lack of activists with disability prepared to run DPO. Also various ways to form DPO were observed.

Conclusion: The idea of being DPO is still not popular in Poland. DPOs in Poland are the minority among a large group of disability related organisations (mainly service providers) and they perceive their position as relatively weak especially towards public policy makers. But simultaneously awareness of being DPO and its significance is growing.

Keywords: disability movement, disabled people's organisations

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*Speaker

Living the Cyborg life ? A critical and pragmatic approach to prosthesis use in amputee's daily life

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Some contemporary amputees equipped with robotic prostheses are portrayed in the media and cultural representations as " bionic men " or " cyborgs " (as a famous example, James Young and his futuristic" Konami " prosthesis, inspired by a videogame). These designations disrupt the concept of disability in amputees' identity and representations. It also questions the relationship between the body and its prostheses, assuming a form of fusion or harmony between mechanics and the organism. Yet, beyond these sensationalist discourses, what can we observe through the practical uses of these devices?
The purpose of this contribution will be to analyse, based on interviews and grounded observations with amputees, the reality of this "cyborg" identity for people using high-tech prostheses. A critical and pragmatic interpretation will be proposed on technological promises in the cultural field, by checking their validity, their possibilities and especially their limits, as settled in a daily life context.

It will be shown that this cultural cyborgic identity is kind of an illusion. Indeed, prostheses hide many limits and cannot be considered as a satisfying answer to many disability situations of amputated persons, especially given that the amputated body also seems to reveal a constant resistance to prosthetic technologies. These flaws will be analysed through a comparative approach between the media discourses and the users' accounts.

Keywords: amputation, prosthesis, cyborg, cultural representations, deconstruction, grounded theory

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*Speaker

Further Findings from Bridging the Gap, Disability and development in 4 African countries.

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, Mark Carew , Ellie Cole

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This paper will present findings from an in-depth analysis of data generated in our 4 country ESRC/DFID comparative study (ES/L008785/1) on disability and development. We will concentrate here on comparing what additional findings can be generated using the Washington Group Extended Set of Questions verses the Washington Group Short Set of Questions and the relevance of choices related to what version of the methodology is used, to researchers.

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*Speaker

Tackling a blind spot of the "inclusive university" - The PROMI project for doctoral students with disabilities

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Background:

While various measures are being taken under the label of "inclusive university" to address the needs of students with disabilities, German universities haven't paid attention to their academic staff (doctoral students and researchers with disabilities) so far nor have they engaged in the analysis and reduction of barriers or the promotion of equal opportunities (Bauer, Groth, Niehaus & Kaul, 2016). Thus the PROMI project for doctoral students with disabilities is designed as a combination of a research and practice project to implement inclusive structures and processes at universities and to identify barriers and enablers.

Methods:

Funded by the Federal Ministry of Labour and Social Affairs the project provides 45 additional part-time jobs for severely disabled doctoral students at 21 cooperating universities nationwide. The formative and participatory evaluation of the project focuses on experiences of the different stakeholders that are involved in the project (e.g. doctoral students with disabilities, doctoral supervisors, graduate schools). It combines qualitative (interviews, group discussions, future workshops) and quantitative (questionnaires) methods.

Results and Outlook

There has been a wide interest of universities as well as university graduates with disabilities to participate in the project. This indicates that the "inclusive university" is an upcoming topic that has been raised by the UN-CRPD. PROMI contributes to broaden the understanding of what "inclusive university" means. The evaluation indicates that bureaucratic problems regarding the provision of rehabilitation services are a main barrier. On the university level a good cooperation of the relevant stakeholders is an important enabler.

References
Bauer, J., Groth, S., Niehaus, M. & Kaul, T. (2016). Auf dem Weg zur Promotion: Strukturelle Hürden und individuelle Herausforderungen für Promovierende mit Behinderungen. In U. Klein & IBS (Hrsg.), *Inklusive Hochschule. Neue Perspektiven für Praxis und Forschung*. Weinheim: Beltz Juventa. 222-235.

Keywords: higher education, inclusive university, doctoral studies, PROMI project

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*Speaker

Presenting the African Network for Evidence-to-Action in Disability (AfriNEAD): A Regional Disability Network based at Stellenbosch University, Cape Town South Africa

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The danger of accumulation of research evidence without developing practical solutions to address the ways in which society could become more responsive to, and more inclusive of persons with disability is seen as problematic in the area of disability research. Questions have been asked regarding the available research evidence whether it has managed to realize the rights of disabled people within a Pan - African perspective. The challenge was clear: it was not about more research that is needed; it was 'improved' research and research that can be translated into policy and practice. This has given birth to the African Network for Evidence-to- Action in Disability (AfriNEAD). AfriNEAD seeks solutions to the removal of obstacles and barriers by focusing in bridging the "know-how" across a broad range of critical relevant stakeholders involved in the realisation of the rights of disabled people in Africa. The network was incepted in November 2007. Four (4) bi-annual conferences had been tabled since its inception. The aim of this paper is to present AfriNEAD and its quest to assist researchers in using research evidence as a tool to realize the rights of disabled people in Africa.

Keywords: Research Evidence, African Perspective

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*Speaker

Entry Denied: A history of Canada's immigration policies and their consequences for people with disabilities and their families.

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Canada is universally known for its liberal democratic values and its progressive ideals toward persons living abroad who wish to immigrate to Canada. However, if one is disabled or if one has a family member with disabilities Canadian borders are closed to most of these individuals. Denying permission to immigrate to Canada to people with disabilities is detailed in the Canadian Immigration and Refugee Protection Act which assigns a large percentage of this population to the inadmissible category which ultimately means that they and their family members will not be permitted to immigrate to Canada.

The presentation will be composed of three intersecting parts that include: a historical examination of immigration policies; recent challenges by Canadian disability rights activists and case examples of people being denied entry. This presentation explores Canadian immigration policies and legislation beginning with its first immigration act of 1869 to the present era Immigration and Refugee Protection Act to show that immigration policies, for people with disabilities, have received minimal changes during the past 150 years. In recent years Canada's immigration policies have been challenged by various advocates and disability groups such as the Council of Canadians with Disabilities and some of these court challenges will be presented. The presentation will personalize the policies by discussing a number of real life examples of people who were denied entry and of people who challenged immigration policies in the courts and were successful in obtaining permission to remain in Canada.

It is anticipated that the presentation will cover a number of areas listed by ALTER: History of disability, migration, segregation, human rights and advocacy.

Keywords: disability, immigration, inadmissible, excessive demand, migration, human rights, inclusion.

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*Speaker

Production of knowledge in the discourse of German Special Education: ADHD as a category of 'abnormal' behavior.

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The construction of the ADHD phenomenon relies on perceptions of what is considered as 'normal' student behaviour. Therefore, it can be interpreted as a discursively constructed version of 'abnormal' behaviour, which goes along with references to medical and educational knowledge systems.

In my talk, I would like to discuss key findings of my study, where I examined the construction of ADHD in the discourse of German Special Education. Based on a theoretical framework, which combines aspects of the 'Sociology of Knowledge' (see Berger/Luckmann 1992) and 'Theories of Normalism' (see Link 1997), the body of investigation has been analysed with a discourse analytical approach (see Foucault 1981). The analysis covers 74 articles published in Journals and Handbooks on the field of Special Education from 2000-2015.

Focussing on the production of knowledge, I will highlight not only technologies of normification and normalization in the discourse of Special Education, but also emphasise the construction of the subject of ADHD, which appears to be historically and culturally contingent. Locating my approach within Disability Studies in Education, I will point out potentials of transferring theoretical approaches of Disability Studies to analyse educational knowledge systems and to enrich current debates on disability and Inclusive Education.

Keywords: Disability, Normality, knowledge production, Disability in Education

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*Speaker

Subjects of Inclusion

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Dis/ability and the associated desire for inclusion are often thought in relation to the abilities and possibilities of individual subjects. Following a cultural approach, we understand impairment, disability and normality as generated effects - through academic knowledge, mass media, everyday discourses and symbolic representations, and therefore not as natural fact, but as naturalized difference (Waldschmidt 2017). And thinking about the *Subject of Inclusion*, we consider the individual subject as a category of normalization within socio-cultural production. In critical demarcation to an individual understanding of the subject we argue that the *Subject of Inclusion* should be thought of as a distributed or dispersed one, as an element of a complex network or a network itself. These dispersed subjects are unstable in their constitution as networks and are constantly reassembled, in the sense of becoming (Deleuze) – from various human and non-human actors.

After a historical reconstruction of the individual subject we are introducing a relational-materialistic perspective with e.g. Niewöhner and Kontopidis, and challenge the binarity of subjects and objects and propose to transfer agency to a network of different heterogeneous entities (Niewöhner and Kontopodis, 2008: 10). Here it must be taken into account that these entities involved in the constitution of subjectivity have expanded to complex technologies since digitality. What we offer, then, with Karen Barad's theory of agential realism, is a posthuman perspective on inclusion in which inclusion and its subjects are not produced only in intersubjective symbolic, language-based discourses but in complex "intra-actions" (Barad 2012) between humans, things, discourses, practises, technological means and more.

With an actor-theoretical perspective, with which both social variables and power relations are taken into account, we ask for new premises for inclusive research, especially with regard to education.

Keywords: Inclusion, Subjectivity, Technology, Agency, Intra, Action, Agential Realism, Education, Culture, Materiality

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*Speaker

Biopolitical Knowledge and Modernism. Disability Studies Perspectives on German and Austrian Literature, Theatre and Film

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The relation between modernist aesthetics and biopolitics has so far rarely been analyzed by
literary and cultural studies (see Siebers 2010; Harrasser 2010). In this paper I explore this context with regard to German and Austrian literature, theatre and film of the 1920s and 1930s by bringing together perspectives of the history of knowledge with cultural disability studies. The term biopolitical knowledge refers to scientific debates (e.g. in medicine, anthropology, biology, sociology) as well as to popular and political discourses on Darwinism, degeneration, race theory, and eugenics ("Rassenhygiene"). The omnipresent representations of disability in modernist literature and art (see Poore 2008) can be related to this emergence of biopolitical knowledge. Literary texts by authors as Ödön von Horváth (Glaube, Liebe Hoffnung, Geschichten aus dem Wiener Wald), Veza Canetti (Die gelbe Straße) and Elias Canetti (Die Blendung) not only refer to popular and scientific knowledge on reproduction, eugenics, physical hygiene and disability, they also reflect on scientific and popular practices related to biopolitics such as anatomic theatre, panopticon and the freakshow. While those practices of exhibiting and performance function as aesthetic model they are also used to criticize normalizing effects and body regulations (Garland Thomson 1996). The paper aims at two goals: Firstly, I want to discuss perspectives regarding the history of knowledge for disability studies. Secondly I aim to make disability studies functional for understanding aesthetic modernism.

Bibliography

Garland Thomson, Rosemarie (Ed.) (1996): Freakery. Cultural Spectacles of the Extraordinary Body. New York/London.

Harrasser, Karin (2010): Exzentrische Empfindung. Raoul Hausmann und die Prothetik der Zwischenkriegszeit. In: Edinburgh German Yearbook 4.

Poore, Carol (2008): Disability in Twentieth-Century German Culture. Ann Arbor, Mich.

Siebers, Tobin (2010): Disability Aesthetics. Ann Arbor.

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*Speaker

The fragility of the body – deliberations of a general anthropological conceptualization

Marianne Hirschberg * [1,2]

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Though Disability Studies provided the theoretical background for the shift from the Medical Model to the Social Model of Disability access to society is still framed by ableism and the strife to efficiency. Contrasting this, I would like to discuss deliberations on a conceptualization of everybody's body as potentially fragile or vulnerable referring to Tervooren (German discourse), Zola or Davis (Angloamerican discourse).
Human beings feel pain, are vulnerable and dependent on others (regarding breaking one's leg, having breast cancer or being blind...). So, pain is a human experience, whether people are chronically ill, disabled or able-bodied. Therefore, persons are temporarily or momentarily able-bodied (Zola 1993). The spectrum of health or functioning and different abilities replaces the former perspective of a dichotomy between the construction of normalcy and of deviance (disease/health or disability/ability). With this viewpoint, vulnerability and dependance are human conditions of every person.

Methodologically, I refer to discourse theory and analysis of the discourse in Disability Studies and interdisciplinary studies on the conceptualisation of the body. Thereby, I analyse the discourse of the body in the spectrum of dis_ability.
I argue that the public discourse of inclusion ignores the mainstream mindset of ableism. With the possibility of being only temporarily able-bodied, inclusion cannot be achieved without regarding the potentially developing fragility of each body and the challenges resulting from it.

Keywords: fragility, body, disability, ableism

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*Speaker

The understanding of disability as a key success factor in inclusive adult education: Analysis of the professional habitus of teachers in inclusive adult education

Marianne Hirschberg * [1], Helge Stobrawe *

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According to the Convention on the Rights of Persons with Disabilities (CRPD), the professionalization of teachers for an inclusive education system is needed (art. 24 para. 4&5 CRPD). Given the fact that 71% of pupils of special schools in Germany leave these schools without graduation, second chance education is important for disabled people. Nevertheless, little is known about teachers of groups of disabled and non-disabled adult participants.

In the context of professionalization according to the CRPD, I focus on the professional habitus of teachers in adult education. The questions is whether and how they have adopted the perspective on disability being the result of the interaction of impairments and societal barriers (CRPD art. 1) and how they work with inclusive adult groups and align their teaching style by focusing on the removal of barriers (art. 24 para. 4 CRPD, Hirschberg/Papadopoulos 2016).

The data from group discussions with teachers will be evaluated using Grounded Theory according to the approach of Charmaz (2014). The starting point for the analysis is based on Bourdieu's concept of habitus (2010) linked with Mead's theory of symbol-mediated interaction (2015) and the subjective learning theory by Holzkamp (1995).

The outcomes are part of a PhD project affiliated to the project "Inclusive Education in Literacy Training and Second Chance Education – Qualifications, Competencies and Needs of Teachers and pedagogical Staff" (INAZ).

Keywords: CRPD, inclusive adult education, professional habitus

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*Speaker

Second Chance for Qualification?! The Professionalization of Teachers in Adult Education and the Right to Education without Discrimination on the Basis of equal Opportunity for Persons with Disabilities

Marianne Hirschberg * [1], Helge Stobrawe *

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71% of pupils from special schools in Germany leave school without any graduation (BMAS 2016, p. 93). Therefore, second chance education is important for disabled people offering an alternative way to be graduated later as adults.

According to the Convention on the Rights of Persons with Disabilities (CRPD), the professionalization of teachers for an inclusive education system is needed (art. 24 para. 4 & 5 CRPD). It refers to all levels of the education systems and to lifelong learning and includes the provision of reasonable accommodation (Art. 2 CRPD; Hirschberg/Papadopoulos 2016). Inclusive education does not end with or without reaching a school-leaving qualification.

With our contribution we would like to present first results of our research project "Inclusive Education in Literacy Training and Second Chance Education – Qualifications, Competencies and Needs of teachers and pedagogical staff". The aim of this project is to develop an advanced training module for adult education teachers.

Methodologically, we conducted three group discussions with teachers in adult education. On this basis we will develop a questionnaire to gather information by teachers in adult education nationwide. Both surveys are guided by the question which kind of key success factors for inclusive education can be identified and which resistances exist. The findings will have been analyzed via grounded theory until September 2019. Valid and new outcomes are to be expected being discussed from a human rights perspective.

Keywords: CRPD, inclusive adult education

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*Speaker

Contribution of the Kyrgyz disability movement towards disability inclusive university curriculum: Experiences of the EU Social Protection System Programmes

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This paper focuses on how the perception of disability, which is too often profoundly negative and charity-oriented, is challenged through the trainings of trainers (ToTs) under the framework of the EU-SPS Programme in Kyrgyzstan in 2017-2018. First, the historical background of the Soviet policy and practice is introduced to set the scene. Second, the EU-SPS is introduced that has implemented a few ToTs to university lecturers who are teaching social work discipline in Kyrgyz universities in Bishkek and Osh Cities. The EU-SPS was led by Kyrgyz and Finnish organizations of persons with disabilities where a Kyrgyz woman with a disability played the central role. The third and main part introduces discussions held and changes made towards disability inclusion in the Kyrgyz universities. For instance, after the exposure to different approaches to disabilities, the university lecturers realized that they had been reinforcing the social marginalization of persons with disabilities through their teachings. Today, they teach disabilities from many points of views including socially constructed aspects of disabilities and human rights of persons with disabilities using the newly produced teaching module. Last, the paper discusses on opportunities and risks of university teaching for disability inclusion more in general beyond the Kyrgyz context and link the findings with the Convention on the Rights of Persons with Disabilities.

Keywords: Kyrgyzstan, university education, disability inclusion, disability movement

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[*]Speaker

At work with dual sensory loss

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Introduction and objective: People with dual sensory loss is a group subjected to discrimination and ignorance (Johansson, 2017). The UN Convention on the Rights of Persons with Disabilities, and the Convention on the Rights of Persons with Disabilities (CRPD) should ensure disabled people the right to equal access to all sections of society. The aim of this study is to capture the experiences persons with acquired dual sensory loss have about participation in work life. This study can develop a deeper knowledge and understanding of working with sensory loss, but also about work life for disabled people in general.

Method: Ten persons with acquired dual sensory loss will participate in this qualitative study. The participants are interviewed and the study will identify issues that are strongly linked to participation in working life. The study has a phenomenological research approach and some research questions are; what does the term "participation in working life" mean for people with acquired dual sensory loss? What are the conditions required for them to experience participation in work life?

This study is based on the theory of Lifeworld and the Lived Body and analyzed and interpreted with a hermeneutic method.

Results: At the time of the Alter Conference, we will be done with the interviews and partly done with analysis.

Keywords: acquired dual sensory loss, deafblindness, working life, lifeworld, lived body

[*]Speaker

Disability Temporalities: The emancipatory potential of performing sickness

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Experiences and discourses of disability, impairment, and sickness present a unique perspective on time and temporality. Evocations of crip time (Kafer, Samuels) and sick time (Fazeli) highlight the incompatibility between nonnormative bodies/minds and the unrelenting pace of progress-focused neoliberal capitalism (Crary). Disability art and performance is an important site of refusal against such normative ways of being; a space where artists can resist and propose alternatives to temporal norms.

In this paper I use performance studies methodologies to analyze durational performance works by chronically ill artists Liz Crow (*Bedding Out*) and Leah Lewis (*The Dialysis Project*) that center disability, sickness, and illness. I reveal how-through performatively reworking notions of time-these works conjure an emancipatory potential for people with disabilities. Linking these works to studies on temporality by Elizabeth Freeman, Sarah Sharma, and Lisa Baraitser, I query how the alternative temporalities that these performances present might allow us to rethink the ideas and practices of time that circulate in discourses of disability more broadly (i.e. in medicine and disability legislation).

As a representational and ephemeral art form, performance is closely aligned with issues of time. These performances complicate these issues by linking the specific temporal rhythms of their own bodies and illnesses to wider issues of disability politics. For example, in protest of funding cuts to disability supports Crow enacts a temporal non-compliance by making visible the rest required by her illness, while Lewis's performance centers her reliance on dialysis treatments and thus reveals how her life is structured by a rigid medicalized time. I focus on how these artists enact forms of agency even as they operate within such seemingly restrictive temporalities. In so doing, I demonstrate the importance of considering disability performance as a cultural epistemology that can transform entrenched and oppressive structures of disability and embodiment.

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*Speaker

Inclusion as an organizational development task of general adult education – Opening up to new target groups and cooperations

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By the ratification the UN Convention on the rights of persons with disabilities by the federal republic of Germany in 2009 adult education organisations have been called upon to guarantee equal access for people with disabilities (Beauftr. D. BREg. 2017). In the context of demographic change the demand for inclusive courses in general continuing education will continue to grow in the future (DEAS2014). Institutions of general adult education are facing the task of an inclusive reorganization on an organizational, professional and micro-didactic level (Ackermann u.a. 2013; Kronauer 2013; Heimlich/Behr 2011).
The BMBF-Projekt iQ_EB (2017-2020) analysis and supports the organizational task by developing a concept for the qualification of pedagogical personnel for inclusive education at adult education centers (VHS) with focus on the target group of blind and visually impaired people – in close cooperation with associations in the field of blindness and visuall impairment. On the basis of standardized interviews with the directors of the Hessian VHS in 2018 analyzed with the content analysis (Mayring 1990) the speech explores the question how the organizations of general adult education deal with the task of inclusion.
Two opening strategies are concise: the cooperation efforts targeting established disability care institutions in the public space of the adult education center (Kade/Seitter 2002; Schreiber-Barsch/Fawcett 2017). By opening for new target groups and cooperation partners a reorganization of the institutional structures and the professional self-image becomes necessary. The adult education centers (VHS) use different strategies in this changing process: individual case solutions, special offers for disabled people and institutional cooperations with facilities in the domain of disabled care. To become an inclusive VHS the analyzed adult education centers use different way and invest more or less effort depending on the region, the institutional conditions and the qualifications of the staff.

Keywords: adult education, blind people, visuall impaired people, organisation development, disabled care, inclusion, cooperation

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*Speaker

Different roads to the same target: inclusion through exclusion?

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Two studies were undertaken in former Soviet republics: Ukraine and Moldova. The first study in 2012-2015 was investigating how families with impaired children experience their lives in societies with transition economies, meeting conditions of poverty. As a result of this study, crucial factors, constituting poverty in these families were analysed and identified as a multi-dimensional issue 'for understanding the holistic picture of disaster and hardship leading families with ChildrenwithDisabilities (ChDis) to poverty'(4). The research study has shown that special education as an area of social exclusion and segregation of ChDis and their families, rooted in the principle of socialist humanism and 'DefectologicalEducationalModel (DEM)' (2), played a significant role in the reproduction of poverty in these families. Historical dominance of social exclusion through DEM segregation for disabled learners in the Soviet ideological context, currently is recognised as 'unrealized utopia' (2). Inclusive movement is met as a meaningful challenge in education, generating resistance from families. The second study started in 2019, investigating inclusion in the same countries, adding Sweden as EU country (1, 3). All the data will be analysed corresponding to contextual circumstances, contributing to further illumination of the research question - if social inclusion in life could be reached through segregation in school?

Keywords: children with disabilities, poverty, former Soviet countries

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[*]Speaker

un/doing dis/ability – A Practice Theory approach to working in sheltered and inclusive environments

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Currently in Germany, being disabled – especially being learning disabled – often leads to a professional life in separated settings. Most persons with learning disabilities work in sheltered workshops [Werkstätten für behinderte Menschen], fewer in so called *Inklusionsbetrieben* [inclusive enterprises]. Sheltered workshops have a long history in Germany and provide currently around 300,000 jobs for persons with disabilities. The inclusice enterprises provide inclusive work settings for persons with and without disabilities. Compared to sheltered workshops, they only employ about 12,000 persons with disabilities nationwide. Both sectors, sheltered workshops and inclusive enterprises, are constantly growing, despite the UN-recommendation to abandon sheltered workshops.

One would assume that working in inclusive settings should diminish the stigma of being disabled. My talk will use ethnographic data from both work settings. Using selected examples, I want to show how persons with learning difficulties, as well as their colleagues and professionals, participate in the everyday construction of in/abilities. In both settings, efforts are made to seem 'less disabled' than others. In order to strengthen their own position in an internalized hierarchical system, disabled persons engage in practices of differentiation and ranking. The concept of 'symbolic power', coined by French sociologist Pierre Bourdieu, can help uncover how internalized values disguise power systems at work.

Bourdieu, Pierre. (2002). Masculine Domination.

Campbell, Fiona Kumari. (2009). Contours of Ableism. The Production of Disability and Abledness.

Grover, Chris / Piggott, Linda (Hrsg.). (2015). Disabled People, Work and Welfare. Is employment really the answer?

Keywords: practice theory, sheltered workshops, inclusive labour

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*Speaker

Human rights and the politics of aesthetic body regime among the blind singers in Thailand

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This paper is based on ethnographic fieldwork conducted among blind singers and groups of musician working in the streets of Bangkok. My aim in this paper is to examine the human rights ideology as part of a global political-moral project, one translated locally by the Thailand Association of the Blind and social activists in the country. As a result, human rights as a moral language and an indicator of moral progress at the global level is being transformed into a political tool, to challenge local, institutional morality, which is influenced by Karmic ideology and the rhetoric of *ve-tha-na* (a feeling of pity), and is espoused by Theravada Buddhism. This paper analyzes human rights as a discourse within local life, and also examine the translated, political language of human rights at the local Thai level. It also reveals how the practices and power of human rights language controls the lived reality of blind singers within their local life worlds. Moreover, it will reveals how the unintended consequence of the human rights discourse in Thailand has been to construct the politics of aesthetic body regime among the blind singers to control their ethical modes of behavior. Blind singers have had to learn how to present themselves in line with the requirements of the ruling regime in their everyday life.

Keywords: Human rights discourse, The politics of aesthetic body, Unintended consequence

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*Speaker

Furthering employment? Cross-sectoral cooperation between municipal employment agencies and specialized hospitals for people with mobility impairments

Lena Kjeldsen *† 1, Finn Amby *

1

1 VIA University College – Denmark

For many years, a low employment rate among people with disabilities has been considered a political problem in Europe- also in Denmark (OECD 2010). In spite of this, the employment rate for people with disabilities is more than 30 percent less than that of people without disabilities and have been for more than a decade (Larsen & Høgelund 2015). Explanations of this difference can be found in both the supply-side (people with impairments), the demand-side (businesses) and the matching-side (e.g. municipal job centers)).

In regards to matching, persons with disabilities are more reliant on assistance from job centers when searching for a job (Bredgaard et al., 2016). Other actors such as specialized hospitals assist in this as well. However, research indicate that cross-sectoral cooperation is difficult -also in this field (Amby, 2015; Bryson et al, 2006).

The purpose of this study is to gain insight into the cooperation and potential barriers between the different systems that have importance for the labour market integration of people with mobility impairments. Methodologically, the study consists of qualitative interviews with caseworkers in three municipalities and three specialized hospitals. Our preliminary analysis shows that job centers use the specialized hospitals to some extent. However, the cooperation is not seamless as the two entities operate in different technical terms- one could say different *lifeworlds.*

The implication of this study is that people with mobility impairments experience fragmented assistance that at best does not hinder rehabilitation and at worst works against each other.

Keywords: Mobility impairments, Employment, cross, sectoral cooperation

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Life in the making. Redefinining disability in post-democracies

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The possibilities of genomic management – designer babies, engineered futures, human enhancement and the like – has a powerful symbolic presence. The formation of new cultural practices takes place in the midst of a liberal governmentality influenced by a medical truth regime, insurance policies, statistical data and consumer's choices. As Niklas Rose has underlined in Biopower Today" (2006), we need to develop adequate conceptual tools for the critical analysis of biopolitics in relation to biocapital and bioeconomics. The same can be said concerning the analyses of subjectivation in relation to biopolitical definitions of human/non-human//normal-queer//abled-disabled.

Whereas on one hand, a growing legal and social recognition of people with disabilities can be observed, we find, on the other hand, a silent explosion of utilitarian and ableist ideas in the biopolitical field.

In this contribution, I want to focus on the selective aspects of the biopolitical divide". My argument is twofold: On the one hand, we have to take into account the intersectional quality of biopolitics and its conflicting responsibilities. On the other hand, we have to reflect the key features of a democratic society. Biopolitical modernisation has to be interpreted in terms of a negative dialectic in order to lay bar the challenges for democratic inclusion.

Keywords: Life, Biopolitics, Ableism, Body, Disability

[*]Speaker

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Literally born to be literature creator? On Karol Nahlik - man with Down Syndrome and author of "Love letters to God"

Dorota Krzemińska [*] [1]

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The proposed presentation of mine follows the topic: Disability in the Arts and in Culture. I want to show a piece of (literary) texts written by Karol Nahlik, a man with Down Syndrome who spent his adult life in L'ARCHE Community in Poland and died at the age of 65 in 2018. He appears a remarkable man who used to live in a masque of Down, yet his functioning never seemed to follow "typical" / stereotypical Down Syndrome traits. His interests in history, theology, philosophy and literature made Nahlik a phenomenon within the society of people with intellectual disabilities - he revealed being wise, spirited, reflective man. The one thing, particularly special about him is his literary creativity / literary expression collected into a set of texts entitled "The Śledziejowickie little hums or love letters to God". In my research I employed qualitative methodology: in – depth interview, content analysis and secondary data analysis. I attempt to see Nahlik and his writing in reference to the concepts of A. Giddens, P.L. Berger and T. Luckman to point out, that being a man with Down syndrome was not the only (one) identity of Nahlik and he managed to overcome "typical" cultural scenarios of life in adulthood, imposed by society on people (with disabilities) – concerning a theory of P.G. Heymans.

Berger P. L. , Luckman T., (1991) The social construction of reality. A Treatise in the Sociology of Knowledge. London, Penguin Social Sciences

Giddens A. (1991) Modernity and self – identity. Wiley Blackwell
Heymans P.G. (1992) Lifespan learning: Developmental Tasks and their Management. In: Tuijnman A.C., van der Kamp M. (eds.) Learning across the Lifespan. Theories, Research, Policies. Oxford: Pergamon Press

Keywords: Down Syndrome, intellectual disabilities, literary art, literary expression, identity, social and biographical trajectories and scenarios

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[*]Speaker

Women Aging with Polio in Taiwan: a Life Course Approach

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Despite the growing interest in the ageing experiences of disabled people, little is known about the ageing experience of people living with lifelong impairments and the challenges they face over time. This paper aims to explore the experiences of women ageing with childhood-onset polio in Taiwan, taking a life course approach. The methodology adopted is qualitative, with life history interviews being conducted with ten women with childhood-onset polio aged from 50 to 60 years. All participants contracted polio before the age of five. Analysis of these interviews provides an understanding of what life is like for these women who have grown old with childhood-onset polio, and how their previous life experiences shape their current lives. Women with polio experience multiple oppression based on disability, gender, age and class, and this prevents them from fully participating in society throughout the course of their lives. Lack of early support creates disadvantages for the women, and puts them at a risk as they grow old. Disabled women are often perceived as passive, dependent and weak, but these women's experiences can be read as a counter-narrative to discrimination against disabled women. It shows how disabled women develop strategies to resist oppression and regain control of their lives. The research findings extend the limited understanding of women ageing with lifelong impairments. A number of insights are provided for policy development, service provision and future research.

Keywords: women with disability, gender, ageing, life course approach

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*Speaker
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Disability and Gender Studies. Approaches to an Interweaving in German-Speaking Literature

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Rosemarie Garland-Thomson's groundbreaking study *Extraordinary Bodies* aims to situate Disability Studies in the field of the humanities, drawing on concepts from Gender Studies in order to theorize the category 'disabled'. My lecture takes up this project and discusses the interweaving of Gender and Disability Studies in selected German-speaking texts. Hereby, Judith Butler's concept of drag becomes relevant since the phenomenon of 'disability drag', as Tobin Siebers describes it in *Disability Theory*, can be found both in Max Frisch's novel *Mein Name sei Gantenbein* and in Thomas Bernhard's drama *Der Weltverbesserer*: An abled character stages as disabled – Gantenbein pretends to be blind, the 'Weltverbesserer' pretends to have paralysis in his legs. Just as 'drag' makes it clear that gender is a cultural construct, the performance of 'disability drag' of the characters can be read as a deconstruction of an assumed 'natural truth' of the body. In this context, the texts raise the question of the dis/ability of their characters: Are Gantenbein and the 'Weltverbesserer' disabled because they are perceived and treated as such, or are they abled because there is no impairment? Does the 'cause' of disability lie in the body, in the environment, or, as Garland-Thomson puts it in her article "Misfits", in the 'inappropriate' relationship between both? In the literary texts not only 'disability' but also 'impairment' is up to discussion since the body evades a clear description in both texts and the question of the attribution dis/abled remains open. Impairment, like disability, appears as a product of discursive structures of power and knowledge.Finally, based on this analysis, my lecture will ask to what extent such a transfer of theories, and thus the equation of the categories gender and disability succeeds – hence, my lecture discusses the limits and opportunities of intersectional research.

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*Speaker

Collaboration between Professionals and Parents of Children on the Autism Spectrum in the Swedish Early Intervention System. A qualitative case Study

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[2] University of Gothenburg – Sweden

As widely excepted, a high degree of social participation and quality of life for children with disability requires collaborative partnerships and a shared responsibility of parents and professionals. Parents advocating their children's rights play an essential role in the provision of habilitation services. However, cooperation between professionals and parents can be a challenging task in the field of work with families that have a child with disability. This study aims to explore the collaboration between parents and professionals and the kind of assistance given in the Swedish early intervention practice from a parental point of view. By gaining a deeper understanding of the families' needs for support, one can develop different ways in supporting families, here exemplified by children with a diagnosis in the field of autism spectrum disorder. An empowerment perspective that emphazises the families' capabilities forms the theoretical framework of the research (Askheim & Starrin; Keupp; Nussbaum). Five parents from different Swedish regions participated separately in semi-structured in-depth interviews. The results reveal that parents expect professionals to provide expertise in autism and appropriate habilitation practices. Simultaneously, they express a wish for output orientated methods, by adapting the interventions to the family's personal needs. Moreover, parents raise important issues such as parent support and siblings groups, options for psychosocial counselling for all members of the family and the need of a contact person. Discussed in the context of empowerment, the results show that engaging parents' capabilities to deal with their life situation plays an important role in collaborative processes.

In conclusion, the individuality of the child and their family is as deeply anchored in the Swedish early intervention system as adapting practical support to the family's actual living conditions and environment.

Keywords: Swedish habilitation, parents, collaboration, autism, empowerment, capability approach

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*Speaker

Between protection and exclusion – dis/abled refugees and the asylum interview

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Social work projects and research at the intersection of dis/ability and displacement have recently increased. A main focus of these projects is on the reception conditions of dis/able/d refugees (Westphal und Wansing 2018). The personal interview is one of the most important moments during the asylum process (Achhammer und Herbst 2014: 212). Nevertheless a research gap remains concerning the personal interview during the asylum process.

The asylum procedures directive (2013/32/EU) states regulations for vulnerable refugees (e.g. dis/able/d refugees) in favour of minimizing those barriers. Straimer (2010) though stresses that "due to [...] barriers that asylum seekers with disabilities face, the asylum procedure is likely to remain powerfully exclusionary" (10).

My research project focuses on this gap using a grounded theory approach. Exclusionary barriers are researched using expert interviews with social work professionals, examining the intersection between different laws as well as social work responses. The research further explores the experiences of dis/able/d refugees within their own asylum procedure. The presentation thus aims to contribute to a broader image of exclusionary barriers during asylum interviews, provides a deeper understanding of how and by whom vulnerability is negotiated, and demands political solutions for political problems.

Keywords: asylum procdure, forced migration

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*Speaker

The (De)pathologiziation of Trans*Identity: Envisioning Trans_Mad_Disabled Politics of Solidarity

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The de/pathologization of trans* identity gained growing media attention with the revision of the *Diagnostic and Statistical Manual of Mental Diseases* (DSM) in 2013 and the I*nternational Classification of Deceases* (ICD) in 2018. Discourses around psychopathology and trans* identity fall together in many different ways. Sometimes '*mental disability'*/ Madness and trans* identity are discussed as synonymous, sometimes as causally determinative (working in both directions) and sometimes in clear differentiation to each other. To analyse these discourses, I work with the sociology of knowledge approach to discourse (Keller, Rainer 2005) and autoethnography (Ellis, Carolyn 2004). The material used are trans*specific diagnoses in the DSM and the ICD since 1980; trans*activist statements and reports (as ex. GATE 2011); newspaper articles and my own reflections as part of Trans* and Mad movements.

My analysis show that especially in media, news discourses and fictional representations trans* identity and gender variance has a long history of being labelled '(mentally) disabled' – and as a result being constructed as dangerous and criminal. Medical discourses long understood (and partially still understand) trans*identities as part of psychiatric diagnoses, while listing several other psychiatric diagnoses as differential diagnosis to trans*specific diagnoses. Activist narratives around trans* depathologization often clearly distance trans* identity from other (psycho)pathologized groups, arguing that trans* identity is 'wrongfully' considered a mental disability in differentiation to 'real mental disabilities'. I argue that these narratives reproduce stigmatizing and naturalizing images around Madness and disability and further that they vastly ignore the realities of Mad and disabled trans*persons.

Working with the radical model of disability by A.J. Withers (2012) I envision a trans* movement in solidarity with (wider) Mad and disability movements rather than in clear differentiation to it, specifically looking for narratives and actions of solidarity within claims for the depathologization of trans*.

Keywords: Mad Studies, Transgender Studies, Depathologization, Movement, Diagnosis

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*Speaker

European Disability Histories through Television. Study of the Television Suisse Romande (TSR) archives (1954-2018).

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Part of *Visual studies* are interested in the analysis of explicit and implicit messages broadcast by television streams and in the conditions of their production. Contrarily to precedent french research about disability and television (Lachal & Combrouze, 1998; Grossetête, 2014), our program is designed in a socio-historical perspective to better understand the evolution of social relations of domination, and the processes of social inclusion/exclusion of people with disabilities since 1950.
We are using the audiovisual archives of French-speaking Swiss public television and aims to show through what social debates and power relations, the discourses about disability have been transformed in the Swiss context?

We select television programs that recurrently address the issue of disability during these 7 decades. We look at television content as a virtual world constructed as a reflection of society, which acts in return on the society itself (Macé, 2000). From a contextual model of disability (Fougeyrollas, 2010), we focused on the characters presented in TV programs as "disabled" and the social situations and "situations of disability" in which they are staged.

First analysis of the TV programs selected in the decade 1950-1960, which are mostly religious, will be presented during the communication.

Main references

Fougeyrollas P. (2010). Le funambule, le fil et la toile : transformations réciproques du sens du handicap, Québec, Les Presses de l'Université Laval, 2010, 315 p.

Macé E. (2000). Qu'est-ce qu'une sociologie de la télévision ? Esquisse d'une théorie des rapports sociaux médiatisés. 1. La configuration médiatique de la réalité. *Réseaux,* volume 18, n∘104, 2000. Internet et entreprise. pp. 245-288.
Grossetête M. (2014). Grande cause, petit écran. Le handicap selon la télévision Française (1995-2009), *Genèses,* 2, 95, pp. 49-70.

Keywords: Visual studies, Television, History, Disability, Social change

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Disability Law and Legal Studies

Kim Marshall * [1]

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The central argument of my paper is that Disability Law suffers from the perception of not being seen as a mature subject in its own right. Either it is embraced as part of a 'Disability Studies' Programme or, in the legal academy, is seen as an adjunct to other more 'reputable' and longer established subjects. Disability law, where it is taught and researched, is usually subsumed as a side note of discrimination law within an increasingly overcrowded employment law module. Disability law, aptly in my opinion, does not fit easily within the legal academy because it is not easily pigeonholed. It is not purely an avenue of discrimination law. It has elements of welfare and medical law. It overflows into European law and, arguably, the most interesting developments in disability law are taking place at supranational nation as the UN develops a new construct for the definition of disability – the 'inclusive equality' model. Austerity in the UK has led to stagnation and regression in disability law and this may explain why the subject has not developed further.

Disability Law is generally not offered as subject for study at undergraduate level and the institutions which do tend to offer at postgraduate level in Europe fall into the group that I would term 'the usual suspects – Leeds, Galway, Maastricht. Further, Disability Studies courses tend to be based in 'Rehabilitation' departments.

Date will be sourced empirically from law school websites in England and Wales to show if, and at what level, disability law is offered as a module. A random selection of European Law schools will also be examined for the same information. Data will be presented in tabular form. I believe that this is a new piece of work and that there are minimal existing references.

Keywords: Disability Law, Discrimination, EU, United Nations Convention

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*Speaker

The History and Evolution of Hospital Design Strategies

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When improving our healthcare system, focus is currently put on physical improvement in space like improved hygiene, innovative devices, improved energy performance, improved ergonomics, ... An often overlooked key parameter is the focus on cognitive experiences of people (e.g. the psychic state of the patient, quality of live/work of staff, welcoming of the family). More research in design and a supportive design strategy is needed to understand the user perspectives within healthcare services to guide architects in their design process. This is where Design for All (EU), Universal Design (USA), or Inclusive Design (UK, AU) comes in. It is a design strategy which no longer considers the disabilities of the users but instead focuses on enabling and disabling conditions of the environment. However, the domain lacks design methods and parameters to link user experiences with the design principles.

This study hypothesizes that many architectural design strategies for healthcare environments have a medical objective but neglect a Design for All-strategy with attention for abilities, emotions and experiences.

A literature review is undertaken, and international hospitals are analysed by means of case study reviews and plan annotations. By exploring the historical evolution of hospital design, the paper attempts to identify the determinants which have shaped previous hospital design strategies. The evolution of hospital design is structured into different time frames which mark distinct directions in hospital design. Within each time frame, the role of the hospital as an institution, the design strategies, and the theory which supported design strategies are analysed. Design develops from needs, and the changing needs mark the evolution of the hospital facility. This reshaping of the hospital design may provide opportunities for generating new design conceptualizations.

Consequently, insights may inspire the design community from a medical problem-solving design strategy towards a more socio-cultural design strategy.

Keywords: Design for All, Design Strategy, Hospital Design, History

*Speaker

The CRPD and Law Reform in the United Kingdom

Wayne Martin [*][†] [1]

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The UK submitted its *Initial Report* on compliance with the CRPD in 2011. At the time the UK government's position reflected confidence that Mental Capacity and Mental Health legislation in the UK was largely compliant with the CRPD. In the intervening years, however, questions have been raised about the UK's compliance. These concerns were formulated explicitly by the CRPD Committee in its Concluding Observations on the UK in 2017.

The same period has seen an intensive period of law reform initiatives in all three jurisdictions of the UK. At present writing a Mental Capacity Amendment Bill is being debated in Westminster (even as Brexit consumes all the media attention), and the UK Government recently concluded an independent review of the Mental Health Act calling for, inter alia, an end to discrimination based on disability. Northern Ireland has passed but not implemented an innovative new Mental Capacity Act, and Scottish Government has just announced a review of its Mental Health Act.

In each case, these reform initiatives have been predicated upon a stated intention to "bring a greater focus on human rights." But the approaches taken in trying to fulfil this intention have varied significantly. In this presentation I map out the various approaches that have been taken, and consider the different directions-of-travel that have been marked out for longer-term reform of mental capacity and mental health legislation across the UK. I conclude that although the CRPD Committee's position has convinced few policy makers in the UK, the Convention itself has been an important factor in shaping the reform movement.

Keywords: UN CRPD

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"It was like putting on an sign, saying I'm disabled, by the way'". A qualitative study about the appropriation of wheelchairs in an ableist society.

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The wheelchair is a classic stigma-symbol. In an ableist society it is THE symbol for disability per se and an emblematic counterpart to the souvereign, autonomous subject of the citizen. Rehabilitation sciences' interest in wheelchair use is mostly limited to the question of the right fit and usage, and the individual's wheelchair acceptance. What is often overlooked is why, despite the proven benefit for a lot of people with mobility impairments, wheelchairs are often left in the boxroom or are not acquired at all. My contribution extends an individualised, psychological perspective on wheelchair acceptance to a societal perspective, from a vantage point of Dis/ability Studies. Drawing on works of Goffmann, Davis, McRuer, Campbell, Parr, Watson & Woods, Moser, Reeve and Goodley, I look at the paradox arena in which disabled subjects appropriate technology and model their (re)constructions of dis/ability: Enabling and yet stigmatizing, the wheelchair has an empowering as well as devaluating effect. I also ask what role does an internalisation of ableist discourses and psycho-emotional ableism play. I draw on preliminary results of a study of eight problem centered interviews (Witzel) with people with mobility impairments that I interpret with reference to Grounded Theory methodology (Charmaz). My results suggest that wheelchairs are perceived not only as assistive technology, but as highly volatile symbols that denote a threshold from abledness to disability and that can produce an "outing" as a discredited person (Goffman). The dominant ableist perspective has wheelchairs as signifiers of social failure and physical decay and as limitations of physical autonomy. Longtime wheelchair users perceive and use wheelchairs quite to the contrary, as liberating and flexible tools that enrich their lives but also alter social relationships. My interviewee's narrations show their challenges of grappling with their own take on ableist and potentially disciplining assumptions about their wheelchair use.

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*Speaker

The role of the Centers for Independent Living activism in Disability Policy change: An exploratory study in Portugal and Spain.

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The history of disability policy had been marked, until the first half of the twentieth century, by the monopoly of medical and charitable models that, while defining disability as an individual's problem, attributed to institutional providers the power to decide the life of these people. Only in the 1970s, in the American context of civil rights struggles, the Independent Living paradigm emerged, and with it, the first Center for Independent Living was created in Berkley, as a model of user-led organizations and personal assistance providers. The Centers model, along with the new philosophy, spread over the following years, supported by several activists engaged with Disability Policy in their localities. The present study analyzes the diffusion process of Independent Living ideas in the Iberian countries of Portugal and Spain. The region has traditionally the disability policy guided by social entities led by specialists or volunteers, but rarely by people with disabilities. Thus, the introduction of the Centers is a relevant study object in the field of public policy analysis, since it allows to verify how these new political actors change the agenda-setting about disability theme. The following problem is proposed for research: How have Centers for Independent Living affected disability policy? The article develops a historical analysis of the trajectory of the mobilization actions and advocacy developed by the Centers for Independent Living. The results are grouped in two lines: Cooperation, which corresponds to the strengthening of a coalition to conduct the policy; and Competition: demonstrating the dispute with groups that support traditional models of driving disability policy. The article concludes with a discussion of the analytical model developed and some recommendations for future research.

Keywords: Disability Policy, Independent Living, Policy Change.

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Learning to be included: experiences of community inclusion viewed through a learning lens, for three adults with intellectual disability with individualised funding

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Individualised funding for people with intellectual disability has been trialled in Australia as a means of increasing independence and improving opportunities for community inclusion. This approach to funding has now been rolled out Australia wide in the National Disability Insurance Scheme (NDIS). This paper considers the lived experiences of three adult learners with intellectual disability who had used individualised funding to access informal and non-formal learning opportunities in community settings for more than five years.

Data were collected during seventy-seven hours of participant observation. Twenty interviews with the learners, their parents and support workers supplemented the observational data. Three narratives co-created with the adult learners about their learning experiences in the community are also discussed. Iterative categorization (Neale, 2016) was used to organise the large quantity of qualitative data and thematic analysis (Braun & Clarke, 2012) was then undertaken to further understand the learning experiences.

Findings indicate that with support, learners greatly increased in independence and enjoyed participating and learning, in a variety of mainstream community settings. Access to the community was dependent upon the effective functioning of a triadic system of learning and support between the adult learners, their parents and support workers. However, over time, learners began to increasingly self-direct their own learning experiences and sought some informal learning opportunities in the community for themselves. Conversely, while learners highly valued their experiences in the community all three learners continued to engage in learning opportunities in segregated settings. Some of the possible reasons for this are discussed.

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[*]Speaker

Digital disability divide in modern information economy

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Theoretical and Empirical Background and Relevance: Digital disability divide refers to the gap in information technology ownership and its use between people with disability and normal healthy individuals. Although there is some research on digital disability divide, but there is no measurable solution devised so far. A key reason is that ICT industry is not fully involved in manufacturing ICT products and services for the disabled segment of the society.

Objectives: This research aims to empirically support the existing research on digital disability divide by tracing practical solutions to the unsolved problem of digital disability divide. The hypothesis thus far is that combined efforts of researchers, stake holders including government and NGOs, and ICT industry can minimise the digital disability divide in the modern information economy.

Research design: Empirical work is carried out in the form of mixed-method research by interviewing thirty decision making bodies in ICT industry, healthcare organizations, and research groups. The nature of the interviews is semi-structured. Some of the interviewees are telephonic.

Results: Results indicate that all previous theoretical efforts on digital disability divide alone cannot bring any desirable solution to this problem. When multi-disciplinary research joins hand from academic, healthcare and industrial circles, a lot can be achieved by bringing disabled people into realm of digital inclusion.

Contribution

This research has contributed a strategy to minimize the digital disability divide by confirming the hypothesis posed at the beginning of this research. An expected contribution can also be taken from methodological perspective.

Future directions: ICT is progressively being seen as an instrument to accelerate modern economy. At the same time problem of digital divide is far from being settled. Future empirical efforts into this area are highly recommended with the condition that ICT industry is seriously included in designing innovative research solutions.

Keywords: Digital disability divide, ICT, digital inclusion, grey digital divide

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*Speaker

Critical Voices and Contention: Modes of civil society mobilisation around disability in Russia

Philippa Mullins * [1]

[1] London School of Economics – United Kingdom

My research discusses civil society's responses to Russian state policy around disability. Based on 61 semi-structured interviews conducted in four large cities in European Russia from 2017 to 2018 and analysed thematically, I draw out strategies used by civil society organisations (CSOs) from unregistered, fluid groups to professionalised NGOs and government-organised NGOs (GONGOs) aiming to reposition disability via both legislative and social change.

While CSOs in Russia have been identified as mobilising around disability (Bindman, 2015; Fröhlich, 2012; Klepikova, 2011; Kulmala, 2016), both the medical model of disability and an often-urgent need for medical care (Rasell & Iarskaia-Smirnova, 2014) have led to findings emphasising gap-filling and medical interventions (Thomson, 2006). This is compounded by civil society research finding Russian CSOs more broadly to be channelled into service provision with limited room for contention (Fröhlich, 2012). On this view, the government follows a 'double strategy' which encourages 'the creation of and dialogue with loyal organisations [while increasing] pressure on potentially critical voices' (Pape, 2014, p.31).

In response, my research's focus on disability organisation keeps uppermost questions of rights and advocacy. It demonstrates CSO contention in their understandings of disability and work for legislative and social change, simultaneously rebalancing portrayals of disability CSOs and exemplifying continued criticism of the state by CSOs. Furthermore, it finds that the state's 'double strategy' is experienced in a far more complex manner by CSOs; apparently 'loyal' organisations may perceive themselves as employing 'self-imposed censorship and [...] conscious de-politicization' (Ho & Edmonds, 2008, p.2). Therefore, they may open further possibilities of action by cultivating hidden links with grassroots organisations distant from government. In reopening discussion of the critical voices in disability CSOs, my presentation supports wider discussion of power dynamics and being critical, and how CSOs may negotiate state restriction in aiming for change.

Keywords: Civil society, contention, power imbalance, grassroots

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*Speaker

Theoretical and Methodological Elements of an Approach for Inclusive Education at School

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Educative experience regarding people with disabilities leads the international debate towards the development of inclusive learning contexts. Nonetheless, the theoretical and methodological principles of an approach able to ensure the development of inclusive education have to be outlined, as a core topic in the field of Special Pedagogy.

Data collected using explorative questionnaires during a tree-years survey in the schools of an Italian region show the evolution of the school context. The qualitative investigation on three macro-dimensions (the perception of diversity, the didactical and methodological attitude, the wellbeing of students) reveals an increasing and solid awareness among teachers.

Results confirm that inclusion processes at school are attainable only throughout a list of clear methodological principles: 1) a valorising attitude towards diversity; 2) the development of an orienting learning process; 3) the plural and flexible use of both methodologies and strategies; 4) the enhancement of a collaborative work style; 5) the engagement in a continuous training process.

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*Speaker
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Inclusive education for pupils with disabilities in France: what do teachers say?

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Inclusive education implies changes and upheavals in both the teaching practices and the school organization as a whole. Inclusive education implies a paradigm shift where the conditions for success are based on the ability of the school to adapt to the diversity of the public it serves (Dyson et al., 1999, Plaisance et al., 2007). Therefore the current situation leads us to reflect on the arrangements defined and put in place to accommodate and support pupils with disabilities in their schooling in France (since the 2005 law). The aim of the research is to evaluate the quality of school devices. Our research concerns a population of 68 French teachers.

The model of multidimensional evaluation of the quality of the educational devices borrowed from Tremblay (2012) is used, A questionnaire with proposals for answers was administered to primary school teachers.

The dimensions studied are as follows: The relevance of the objectives, the characteristics of the population of the scheme, the adequacy of resources, the reliability of actions, the effectiveness and the flexibility of the system.

Keywords: Key, words: Disability, educational system, inclusive education, teachers, France

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[*]Speaker

"Disability in Legislative Processes"

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The paper will focus on legal perspectives of disability and participation, and provides a comparative analysis of UN-CRPD implementation processes in Austria and Germany. A close consultation with and an active involvement of persons with disabilities in the development and implementation of legislations and policies to serve the implementation of the Convention, and in other decision-making processes concerning issues relating to persons with disabilities is stated in article 4 par. 3 UN-CRPD. The mentioned consultation and the involvement constitute shapes of participation, and should be conducted through the representative organizations of persons with disabilities. The preferable implementation represents all various types of disability. In the disability communities exist disputes on representation, especially when it comes to representation through national disability organizations. The current analysis focuses on how the state parties implement and fulfill their obligation outlined by the UN-CRPD. They receive support from the General Comment No. 7, which provides guidelines on how to understand and interpret article 4 par. 3 UN-CRPD and recognizes participation as a principle, an obligation and cross-cutting issue. In New Zealand the Chief Executives' Group on Disability Issues developed fundamental principles – the "New principles of engagement" – to guarantee a practice of involvement of disabled persons in line with NZ's interpretation of Art 4 (3). Civil society involvement was put into practice in national legislative procedures in the two case studies. In Germany the Bundesteilhabegesetz was elaborated accompanied by a participative process. This process was realized in ten well organized meetings within one year. In Austria (Tyrol) the Tiroler Teilhabesgesetz came into force in 2018. The content of the new law was developed in a specific form of participation, a so called "Legislatives Theater". The analysis comparatively evaluates the measures taken to ensure civil society participation and their respective successes or shortcomings.

Keywords: Disability, Participation, legislative processes

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[*]Speaker

The myths and the facts about autism and work in Portugal

José Nogueira [*] [1,2]

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[2] José Miguel Nogueira – Rua Dr. António Manuel Gamito, nº2, 1º dirt, 2900-056, Setúbal, Portugal

The integration of people with autism in the labour market is not an easy task, but it is an important factor for their inclusion. In Portugal, the right to non-discrimination in employment is enshrined in national legislation. Portugal has also specific active employment measures for people with disabilities. This presentation aims to discuss the developments on access and participation of people with autism in the labour market in Portugal. Firstly, the research attempts to understand features such as: i) role of the active employment measures and another public incentives; ii) the contribution of organizations of persons with autism and the public training centres; iii) the main barriers to the participation in the labour market; and iv) the role of people with autism and their families in the activation process. Secondly, the presentation also allows showing results about the integration of people with autism in Portuguese companies. Results will be presented on: i) the access to a job; ii) the integration process; iii) the professional route; iv) the remuneration policy; and v) the satisfaction of employers and the satisfaction of workers with disabilities about their career. The research is based on quantitative and qualitative data. We compared data from a recent study (Gonçalves & Nogueira, 2012), with information gathered through interviews with key actors, organizations, and families. The results show that when there is a well-defined strategy and proper monitoring for each case, involving a key player within the company, the success is possible.

Keywords: employment, autism, inclusion

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[*]Speaker

International innovative project to empower and support the people with autism in labour market

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The literature and statistical data show that the persons with autism have difficulties in finding a job and keeping it. The difficulties in communication, in the interpersonal relationships and the behavioral issues are important aspects that make their inclusion in employment a great challenge indeed.

This presentation aims to present and discuss the first results of an innovative project to empower and support the people with autism in labour market. The project involves five European countries and brings together universities, NGOs, public services and companies. The project aims hearing autistic people what they think that lacks in their training. Also, aims to training the employers (colleagues, heads and work context) to contribute for their successful employment. Due to the characteristics of people with autism, the course also addresses the transversal competences, including social and daily life skills and independence.

Methodologically, a survey was conducted on a wide range of companies and other employers, such as public services and NGOs. Then focus groups were conducted to young people with autism, their families and to companies (selected after the survey). Based on the results of these focus groups, were developed the curricula of the courses, which will include an internship. Finally, will be create a new European Guide for the effective vocational training of autistic people in order to contribute for their successful employment.

Keywords: employment, autism, labour market

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*Speaker

Exploration of Experiences of Children and Youth with Mobility Impariment: A Case of a Rehabilitation School in Ghana

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This case study explores the experiences of children and youth with mobility impairment who are in Yennim Okyena Rehabilitation School (pseudonym for a rehabilitation school in the Ashanti Region of Ghana) so as to identify educational support systems that will enable them to have quality education. Participants included 2 males and 3 females who are mobility impaired, the head teacher of the school and 5 parents of children and youth with mobility impairment who were engaged in a focus group discussion. Children and youth with mobility impairment were between the ages of 12 and 25. Data was generated through the use of in-depth interviews, focus group interviews, researcher's journal and observation with the aim of identifying common experiences among students and availability of support systems. The data of the research was analysed using 'dedoose', a computerized qualitative data analysis software, which included the use of coding and extraction of themes. The results indicated that (a) the general understanding of disability was based on the medical model of disabilities. (b) The empathy from their student peers and barriers in the physical environment; (c) Unavailability of trained human resources, material resources and grant or money to run day to day activities of the school. Based on these findings, recommendations for activities to change social awareness of disabilities and educational support systems for children and youth with mobility impairment and teacher empowerment are stated in order to promote quality education for such students.

Keywords: Mobility Impairment, Rehabilitative Supports

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[*]Speaker

Technomediation: Music Hearing with Cochlear Implants

Beate Ochsner * , Markus Spöhrer * † 1

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In our talk, we present the results of a media ethnographic study on music hearing practices with cochlear implants (CI) conducted in cooperation with the CI-Center in Freiburg, Germany. We departed from the idea that in contemporary society music is ubiquitary, it gives access to different forms of experiencing and purchasing knowledge, and enables us to take part in social live. The ability of hearing is an equally necessary and unreflected condition. Music challenges deaf or hard-of-hearing persons, and they respond in different ways like sign language, sign dancers, visual jockeys or, a technical solution, the CI. By transmitting incoming acoustic signals to the brain the neuroprosthesis opens interfacing processes between medical technology, audiology, media studies and music or music therapy that are not only of direct use for CI-listeners, but also call for interdisciplinary research projects.

While most medical studies or audiological trainings aim at standardizing and normalizing hearing, our project departed from the premise that CI-hearing practices are part of an interactive process of subjectivation and socialization in and through which technical, medical and socio-cultural decisions and experiences are intertwined. We focused on CI-hearing practices with different music devices, in diverse situations and environments that, partly, cause the transformation of the CI from a therapeutical instrument to a life style product. We elucidated the complex processes of CI-hearing, (hearing) control and self-control, asymmetric power relations, possibilities of deliberately ignoring (not-listening), as well as individual descriptions of affecting and being affected by hearing music with CI. Methodologically we conducted our research by making use of (video)ethnographical tools, questionnaires and standardized interviews, which in a second step were framed by actual theories of dismediation (Mills/Sterne2017) and methods of STS (Schillmeier 2010).

Mills,Mara; Sterne,Jonathan.2017. Dis-mediation In: Ellcessor, Elizabeth. et.al., eds.Disability media studies. NY:: NY UP, 365-378.
Schillmeier, Michael. 2010..Rethinking disability.NY: Routledge

Keywords: technomediation, cochlear implant, music hearing

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An evidence-based road-map for transitioning to an inclusive education system in a resource-constrained country

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In spite of ratifying the Convention on the Rights of Persons with Disabilities, Uganda promotes segregated education over inclusive education. Contrary to Article 24 of the Convention, the Persons with Disabilities Act 2006 merely *encourages* inclusive education, but *requires* the establishment of special schools. This double standard tends to undermine national progress towards realizing SDG #4 on quality and equitable inclusive education. The UN Committee of Experts on the Rights of PWDs recommended that Uganda develops a timeframe for transitioning to an inclusive education system, but there is limited progress towards this direction. Moreover, little is known about the efficacy of existing special schools to promote quality and equitable learning for children with disabilities. Proposals to close special schools and transform them into resource centers lack empirical evidence and clear implementation guidelines. The primary goal of this paper is to present education stakeholders' perspectives regarding whether and how Uganda can/should transition from segregated to inclusive education. A qualitative research study is being conducted in 20 schools in Wakiso and Kampala districts with different education stakeholders. The study seeks to address the following research questions: (a) what is the status of special and inclusive schools in Uganda? (b) What local inclusive education initiatives and practices have worked and how can they be strengthened? (c) What are stakeholders' views regarding transitioning from segregation to inclusive education? (d) What are the barriers and facilitators to implementing inclusive education in Uganda? Key informants interviews and focus group discussions are being conducted to answer these research questions. The study will inform the development of an evidence-based roadmap for implementing inclusive education in Uganda and the on-going process of developing the National Policy on Inclusive Education.

Keywords: Segregation, inclusive education, Uganda, children with disabilities, Uganda

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*Speaker

Conference Opening and Host on behalf of TH Köln

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Today, disability is understood as a multidimensional phenomenon, specific construction, and multifaceted field of research that is researched internationally, comparatively and across disciplines. In Germany, Disability Studies is a relatively young field of research. In international and European countries, on the other hand, there is a longer, extremely diverse research tradition. For the first time in German-speaking countries, ALTER, the European Society for Disability Research, based in Paris, is organising its 8th Annual Conference 2019 at the University of Cologne.
The conference entitled, "Histories, Practices and Policies of Disability" is hosted by:
Prof. Anne Waldschmidt and Curie Lee (International Research Unit in Disability Studies - iDiS, University of Cologne),
Prof. Matthias Otten(TH Köln – University of Applied Sciences) and
Prof. Isabelle Ville (École des Hautes Études en Sciences Sociales - EHESS, Paris).

About TH Köln and the Faculty of Applied Social Sciences:

The University of Applied Sciences is a multi- and inter-disciplinary, culturally diverse university of technology, arts, and sciences. Over 90 full-time, career-integrated, or part-time degree programs are offered to about 5,000 students annually and 26,000 students altogether. Students in TH Köln come from approximately 120 different countries to learn from 430 professors.
The Faculty of Applied Sciences, one of the largest educational institutions for social work in Germany. The faculty offers Bachelor's programs in Social Work and Early Childhood Education and Family Studies, and Master's programs in Counseling and Advocacy in Social Work as well as Pedagogy and Management in Social Work.

Research in various interdisciplinary fields of Social Work, Education and Social Sciences is organized in several independent research groups and inter-institutional projects. The Center for Migration, Intercultural Education and Organisational Development is one of these units led by Professor Matthias Otten as co-director.

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Development and Implementation of Independent Living Policy for People with Disabilities in Taiwan

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This article is reviewing the prompting history independent living policy for persons with disability in Taiwan and explores the current difficulty of implementation. The Welfare Policy of people with disabilities in Taiwan can be traced far back to 1895 when the Japanese colonial government started the policy as a charity and medical model. However the rights of disable people were not enforced officially until 1980s when The Welfare Law for Handicapped Person was passed because of democratization and since then many related education and nursing institutions were established. The idea of independent living for persons with disabilities was a grass-roots movement and was not legislated until 2007 in Taiwan. This article looks into the development of the Independent Living Policy from its historical and cultural context in Taiwan. First it examines the formation of the national policy in different steps and how it is developing and localized in different ways because of the urban-rural gap. Second, the article is to explore the current dilemma of the implementation of Independent Living Policy and to what degree it is against the spirit of CRPD Article 19. I will like to foreground the dispute of de-institutionalisation by examining the self-determination of the case, the representation of the case and the transfer of the hegemony of the social work profession, the anxiety of the parent group and their dilemma of their choice of long-term care service resources.

Keywords: independent living, CRPD, people with disabilities

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*Speaker

The sexuality of people with disability: the opportunity behind a new form of activism in Italy

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This paper investigates the insurgency of activism of disabled people focused on sexuality in Italy. In a context of denial of the sexual life of people with disability, various projects are currently emerging to claim disabled people's right to sexuality and to shape alternative representation. Among these, the political campaign to promote sexual assistant profession made by the Lovegiver Committee is the most disruptive attempt in the public realm.

The work is based on a qualitative research I carried on in 2018 for the final dissertation of the M.A. in Cultural Anthropology to explore discourses, representations and practices about the sexuality of disabled people in the Italian context. Moving from the critical-interpretative approach of Medical Anthropology (Lock and Scheper-Hughes, 1990), I embraced the suggestion of Shakespeare, Gillespie-Sells and Davies (1996) and Plummer (2003) to recognize sexuality as an essential part of life to take into account to fully understand the experience of disability. In this presentation, I will focus specifically on disabled people's perspectives.

Drawing from the Foucaultian connection between sexuality, knowledge and power (2001), we can sustain that the existence (or absence) of discourses about disabled people's sexuality contributes to reproduce our reality, with its prejudices, discrimination and hierarchies. In Italy, hegemonic discourse silences sexuality of disabled people and turns it into a taboo and a problem. Taking into account people with disability point of view allows to reframe the debate in a new way, adding the topic in the realm of "normality" and possibility.

Thus, disabled bodies represent lands where meanings and social contradictions are performed and, at the same time, a space of personal and collective resistance, creativity, and struggle. In this frame, disability appears as an opportunity to rethink sex, bodies and relations among them. Ultimately, it represents the chance to challenge dominant heteronormative culture.

Keywords: Sexuality, disability, activism, sexual assistance, alternative representations, heteronormative culture.

*Speaker

Disability in and outside of the Monastery.

Katalin Pataki * [1]

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My paper examines the integration of medical experts into the thickening bureaucratic network of the Hungarian Kingdom in the 1780s with a special in the the role of state-employed physicians and surgeons in determining who can be considered as disabled or incapable of work. As part of the comprehensive church policies of the Habsburg emperor, Joseph II, the capabilities and incapabilities of monks were especially often subjects of various investigations and the strict obligations for record keeping througout these procedures ensured the production of documents that can serve as great archival sources for the nowadays historian. This paper is based on the files submitted by the provincials of mendicant orders to the *Ungarische Statthalterei* in which each monk and lay brother was listed and a detailed description was provided about each person regarding his suitability for parish work. If old age or some kind of sickness or impairment prevented the monk from fulfilling any (even auxiliary) role at a parish, the testimony of a physician or surgeon had to be attached. My paper extracts data from these testimonies and contrasts them with the previous concepts and standards of incapacities applied in the monastery summarized in the relevant chapters of Johannes Dionysius John's six-volume *Lexicon der k. k. Medizinalgesetze* (Prague, 1790). John's book was based on a seventeenth-century treatise on legal medicine, namely Paolo Zacchia's *Quaestiones medico-legales* (9 vols, 1621-1651) and provided detailed instructions for physicians in which cases a monk could be exempted from the daily duties of his monastery and had to be sent to the infirmary. The comparison reveals how the notion of usefulness changed with the requirement of performing duties not only inside the monastery, but in a parish, and how secularisation influenced our nowadays concepts of disability.

Keywords: secularization, early modern, state formation, ecclesiastical policies, monasteries, infirmaries, parish service, forensic medicine

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*Speaker

Inclusion and recognition in the context of education - a critical theoretical perspective

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This year we celebrate the 25th anniversary for "The Salamanca statement and framework for action on special needs education". 92 governments and 25 international organisations were signatories to a progressive and innovative document stating that education for all demanded a change in the traditions of education and the development of new and inclusive educational practices. This ambition has been reconfirmed in different international contexts. For example, the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) also states that inclusion is a central objective promoting solidarity between students. In the educational policies of the Nordic countries - who were among the original signing governments signing the Salamanca declaration - the inclusive school is a stated objective both in plans and recommendations, and have been so for a long time. There is, however, ample evidence based on research suggesting that inclusive everyday practices are still a rare commodity in Nordic Schools. This paper presents empirical examples of everyday non-inclusive practices where hearing-impaired students experience different forms of discrimination and marginalisation. These examples are discussed in light of neo-Hegelian critical theories promoting the concepts of recognition and struggle. One prominent feature of the empirical example is that they provide insight in practices among hearing impaired students resembling what Erwing Goffman coined "passing". As passing, according to Goffman, is a symptom or a tell-sign indicating that the passing person experiences stigmatisation, these examples highlight both empirical and theoretical aspects of inclusion. The paper argues that inclusion and recognition are intimately intertwined concepts, and that genuine inclusion must comprise the three aspects of recognition suggested by professor Axel Honneth: non-violence, rights and mutual solidarity both between peers and between adult professionals in the school and the diverse community of students they serve.

Keywords: inclusion, hearing, impairment, stigma, critical theory

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*Speaker

Reconnecting to hegemonic masculinity through IT: studying a paraplegic man's educational trajectory

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We have recently concluded a qualitative research on the reconstruction of paraplegic women's and men's educational and working trajectories (Pont, 2018). From a gender perspective, we analysed our male and female paraplegic informers' resuming of their educational or vocational pathways. This process developed under the injunctions of the 'welfare-to-work' (Revillard, 2016) policy of the Swiss Disability Insurance (DI). While confronting the DI's scansions, our informers elaborated empowering strategies which were not only ableist, but also gendered. In particular, paraplegic men restored a relation of 'complicity' (Connell, 2005) to 'hegemonic masculinity' (Connell, 2005), thus attempting to benefit again from the privileges of patriarchy in education or formal work. Our communication will focus on the narrative of one of our male informers, who emancipated himself from the vocational programs of the DI by engaging into a bachelor curriculum in information technology (IT), the command of which is seen to epitomise men's relation to hegemonic masculinity (Collet & Mosconi, 2010). Our informer's narrative indeed shows that he re-established a connection to hegemonic masculinity through both a discourse on the distribution of gendered roles to men and women involved in the IT curriculum, and an almost total obliteration of the experiences of impairment and disablement in his educational environment.

Keywords: Paraplegia, Educational Trajectory, Hegemonic Masculinity, Information Technology (IT)

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*Speaker

From Compensation to Equality? Reflections on National Disability Policies in a Changing Europe and in Transnational Fields

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Disability presents a global challenge to social justice and human rights. The barriers to disabled people's full participation and equality in society have been acknowledged in international law but policy responses vary greatly between different countries and regions of the world. This paper charts and conceptualises the evolution of disability equality, defining disability as a policy field and evidencing how national and transnational factors influence its development. It examines disability equality as a policy project, emergent over the past half century and in the decade since the establishment of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as a global policy framework. It considers legislative structures, policy processes and outcomes for disabled people in Europe – linking global, European and national developments. In the context of European welfare states, disability equality provides a stimulus to re-think our assumptions about multi-level governance, the Europeanization of public policies, and about theories of national policy regimes.

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A positive deviance approach to understanding key features to reducing stigma and fostering social inclusion among people living with Leprosy, Schizophrenia, HIV, and Diabetes in Indonesia

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Stigmatization deny people with disabilities their dignity and potential, and are one of the greatest obstacles to achieving social inclusion in the community. Positive deviance approach may be helpful in improving stigma related to disability and other health conditions by uncovering successful strategies used by high performers or 'positive deviants' who are able to overcome unpleasant experiences of stigma and foster social acceptance and inclusion. This study aimed to explore and identify successful positive deviant strategies employed by people living with four different health conditions – Leprosy, Schizophrenia, HIV, and Diabetes - in Indonesia to manage and overcome stigma in their lives and foster social inclusion. This qualitative study comprised of 40 interviews and 12 focus-group discussions among 80 people (14 positive deviants) living with Leprosy, Schizophrenia, HIV and Diabetes selected through convenience sampling in Jakarta and West Java, Indonesia in 2018. This study found that positive deviants underwent a similar recursive loop of best practices and strategies in three steps. First, the individuals empowered themselves through self-acceptance, positive spiritual beliefs, active use of information, and prioritization of self-care. Second, the persons reclaimed control of their lives and life decisions by selective disclosure, and indifference to others' stigmatizing responses. Third, the persons were driven by passion and desire to help other stigmatized people through advocacy, peer support, and fostering social awareness aiming to elicit public understanding and empathy towards people living with their condition – paving the way to social acceptance and possible inclusion. The three recursive steps of positive deviance - active self-empowerment, reclaiming control of one's life and life choices, and passion and desire to help other stigmatized people - have implications for stigma reduction and social inclusion efforts for stigmatized individuals in Indonesia.

Keywords: Stigma, Inclusion, Positive Deviance, Leprosy, Schizophrenia, HIV, Diabetes

*Speaker

Notions of self: The (auto-)biographical experiences of young disabled people in their journeys towards or away from paid work

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This paper explores the self-conceptions of young disabled people in relation to wage labour in two different welfare state contexts: United Kingdom (with a focus on England) and Germany. It explores how young disabled people with various impairments and from different socioeconomic backgrounds (aged 16 to 26) make sense of their experiences of interacting with the labour market, the educational and vocational training systems, or the benefits system, and how these inform their self-conceptions. These questions are explored with data that has been generated through narrative-style interviews on the topic of imagined futures and paid work. Through this data, we can uncover how neoliberal subjectification processes and processes of disablement function in two relatively distinct welfare state regimes, while also considering elements of convergence in the two national sets of labour market policies and disability policies. By comparing young disabled people's pathways from school to work as presented in their own narratives, and complementing this data with a wider understanding of the economic and welfare state system they live in, we can uncover the disabling commonalities that stem from wage labour capitalism, as well as understand how different social structures and logics of governing disability affect the life course and pathways that young disabled people consider for themselves, and those they are able to pursue. When analysing the biographical data, it is also vital to consider the positionality of the researcher, who grew up in Germany and now resides in the UK. While many would consider the researcher still part of the group of young disabled people, a reflexive understanding of one's own biography is necessary to question whether the present study qualifies as peer-research. Thus, a reflection on how autobiographical experiences shape data generation and analysis in this comparative qualitative study is needed.

Keywords: biographies, work, labour markets, young people, selfconceptions, comparative social policy, emotions, futures

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*Speaker

Specialization in the disability sector: insights into a less visible form of labor market segmentation

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Disabled people face manifold inequalities on the labor market (Bessière, 2015 ; Schur, Kruse et Blanck, 2013). Compared to more common measures in terms of employment rates, skill levels and work conditions, the concentration of disabled workers in disability-related occupations (working for a disability organization or specializing in disability in their occupation) represents a less visible and less documented aspect of this labor market segmentation.

This paper explores the processes through which disabled people adopt such specialization, and the meanings they endow it with. It is based on the exploitation of a serendipitous finding which emerged throughout the course of a life-story research project on the reception of disability policy in France (Revillard, 2017). Biographical interviews were conducted with 30 people with either mobility or visual impairments.

The content analysis of the biographical interviews reveals the importance and various manifestations of this phenomenon of occupational concentration in the disability sector. It also shows that its meaning for disabled people is ambivalent. Specialization in the disability sector can be experienced as a means of work integration as well as a form of segregation, and it is in fact variedly experienced as an opportunity and as a constraint. I identify three processes through which disabled people specialize in disability-related occupations, which also shed light on the meaning they convey to this specialization: specialization as a consequence of reclassification, specialization constrained by a lack of other opportunities, and specialization as a positive choice.

Keywords: France, qualitative methods, employment, segregation

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[*]Speaker

Inclusive education as a work from below: Focus on a French experimental device

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For more than a decade, international organizations like OECD and UNO have sustained the right to education for all children with disabilities. As a result inclusive practices tend to reshape the foundations and the norms of educational systems (Clark, Dyson and Millward 1995; Ebersold 2009). In France, children with disabilities have long been educated in specialized institutions. Since 2005, legislative texts and administrative framework have increasingly recognized education of all children in ordinary schools as a major goal for the whole education system. However, recent research shows that the implementation of this shift toward inclusive education is far from self-evident (Buisson-Fenet and Rey 2018). In this context, both the National Education sector and the medico-social sector have been developing a variety of inclusive practices. Based on the in-depth qualitative study of a French inclusive device consisting in a team of social, educational and care professionals embedded in an ordinary secondary school, we will examine how intersectoral boundaries can be worked and crossed "from below". We will study the day-to-day reflexive work by which professionals from both sectors try to make these borders more porous, and the way this inclusive work affects the schooling experience of the students involved. The article will be based on about twenty interviews with actors from both sectors and students, and about ten ethnographical observations made within the school.
References:

Buisson-Fenet H., Rey O. (eds.), 2018, Inclure le handicap, recomposer l'école ?, Lyon, ENS Éditions

Clark C., Dyson A. et Millward A., 1995, Towards inclusive schools?, London, D. Fulton.
Ebersold S., 2009, " Autour du mot "Inclusion" ", Recherche et formation, 2009, n∘61, p. 71-83

Keywords: inclusive education, French case, cross sector, qualitative study

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The scandal and everyday life: Contergan as a caesura in the history of West German family care for children with disabilities

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Although *Thalidomide* was featured in drugs sold worldwide during the late 1950s and early 1960s, nowhere did it emerge a decisive political turning point as in West Germany. Here, the product *Contergan* prenatally altered the limbs of thousands of unborn children. While *Contergan*'s alienating effect on the relationship of politics, law and medicine (Lenhard-Schramm, 2016) and its impact on political and public discourses (Crumbach, 2018) are well documented, little is known about its influence on the everyday lives of the impacted families. Based on parental ego-documents, disability activist material and contemporary journals, this paper argues that the *Contergan* complex and its immediate aftermath radically transformed the ways in which care for disabled people was discussed and enacted in West Germany. Not only did its media coverage inaugurate a new visual poetics of disability, but by moralizing disability as a family burden, parents could for the first time after WWII publically scandalize poor social policies for *all* children with disabilities. Yet, their demands for new therapeutic measure, special educational facilities and prosthetic devices had a twofold effect. While empowering parents, *Contergan* stabilized public perceptions that disabled children were a problem and constant liability for family stability by dwelling on their assumed inability to live independently. By further tightening parental control and reaffirming expert authority, the scandal left the actual subjects affected with little power over their own lives. As the paper will show, these claims to agency had to be reasserted by the lasting activism of self-advocate groups that formed in the 1970s. Placing the case in European disability history, the paper will discuss whether the ambivalent legacy of *Contergan* is at the core of a West German *Sonderweg* [special path] after World War II.

Keywords: caesuras and long term developments of European disability histories, international comparisons of European disability histories, care practices, special educational practices, transsystemic comparisons, Disability and time experiences

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[*]Speaker

Disabled people's experiences of social disparities in cancer care

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Access to healthcare is a multifaceted issue. For services to be accessible, they need to be available, affordable, relevant, physically accessible, and acceptable to service users, including disabled people. There is increasing evidence that disabled people face problems in several of these dimensions, leading to inequities in access. In this paper, we explore the experiences of disabled people with physical impairments in the United Kingdom as they access cancer services, from screening to therapy and follow-up. Our aim is to explore what happens when people with physical impairments seek to access cancer services and to investigate the nature of any problems they face. Using empirical data from an interview-based study conducted in the United Kingdom, we treat each participant as a case study, showcasing different aspects of engaging with cancer services. We argue that disabled people often have to navigate a healthcare system that demonstrates lack of awareness regarding their needs, leading to negative experiences of care. We suggest that the experiences of disabled people represent forms of microaggressions inflicted on them. The clinical encounter is a main arena where aggressions, such as the invisibilisation of needs, are experienced. Aggressions are also experienced at the broader, systemic level and can restrict disabled people's access to quality healthcare.

Keywords: microagressions, social disparities, access to healthcare, human rights

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*Speaker

Disability Research methods, conveying from a human rights model and critical disability studies

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The live experiences of people with disabilities are hard to capture in academic research, understanding and explaining disability interactions amongst different contexts is challenging. Furthermore, producing a disability research agenda that is critical and emancipatory for people with disabilities is constantly thought-provoking and hard to attain. Nevertheless, disability research has produced critical approaches that contest the mainstream charity and medical approaches that addressed people with disabilities as objects of pity and disability as illness. The United Nations Convention for the Rights of Persons with Disabilities (CRPD) recognizes people with disabilities as subjects of rights and alongside the disability community has been promoting a human right approach. Human rights-based approaches (HRBA) research methods advance from principles such as participation, non-discrimination and accountably (OHCHR, 2006). However, HRBA are insufficient to understand power relations and structures of all forms of discrimination against people with disabilities.Critical Disability Studies (CDS) is a global field that recognizes power structures that go beyond the binary concept of impairment and body disabled vs. non-disabled. This paper argues the need to address new methods to explain how the "body" matters from an inter/intra-sectionality approach, meaning that disability interacts with other forms of oppression such as sex, gender, age, migration status, ethnicity and nationality (Goodley, 2013). The paper will critically analyse from secondary resources what human rights-based approaches are. Secondly, this paper will explore CDS and explain their main characteristics and the methods used. The third part will compare the epistemological paradigm and methods of both the HRBA and the CDS. In the end, this paper advocates for an ongoing revision of disability research methods that allows room for improvement and understands that there is not a solo approach that can explain disability.

Keywords: Disability research methods, human rights, based approaches, critical disability studies

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*Speaker

The Cosmopolitics of Dis/ability Experience - A Manifesto

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Dis/ability experience can neither be reduced to a mere bodily/mental impairment nor understood in separation from it as a mere societal phenomena. Rather, people with disabilities can be understood as cosmo-political actors that disrupt, question and alter the very understanding of what is seen as human bodies and minds, what is maintained, expected and performed as taken for granted, embodied and materialised social orderings. Drawing on empirical work about dementia and people with visual disabilities this lecture suggests a conceptual framework of disability beyond the split between social and biomedical accounts.

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Discursive constructions of physical and sensorial disabilities in the 17th and 18th centuries

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In my completed habilitation thesis, I've analysed the perception and construction of physical and sensorial disabilities in various discourses in 17th- and 18th-century Western and Central Europe (Britain, France, Germany). Newspapers and journals were used as sources. The main goals and results of the study were the following ones: Assuming that an independent disability discourse wasn't in existence yet, the study aimed at identifying discourses in which disabilities regularly appeared: as a subject, as an argument, as a metaphor. Four such discourses were identified: discourses of poverty and poor relief, of extraordinary corporealities, of illness and its cure, and of pedagogy. Furthermore, the study aimed at reconstructing the images of disabilities and disabled people formed in each of these discourses, at analysing the relationships between them and at looking for changes over time. It could be shown a) that disabilities and disabled people were constantly functionalised for the sake of purposes that often had little direct relation with them: e.g., they served as examples for various theories and as metaphors or allegories in artistic contexts, b) that while there was a dense interplay between the four above-mentioned discourses, the images constructed by them were various and sometimes incommensurable, c) that while the enlightenment brought new ideas into play, what is striking are strong continuities of tropes and narratives of disability. Depending on the wishes of the conveners I could highlight selected aspects of the study or give an overview of its main results.

Keywords: discourses, seventeenth and eighteenth centuries, poor relief, medicine, pedagogy

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[*]Speaker

1971: From Ulbricht to Honecker – A Caesura in the GDR Disability History of Care and Education?

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In the early years of the German Democratic Republic, disability was widely viewed as incompatible with socialist conceptions of society. Consequently, people with disabilities were largely absent from public awareness and discourse for a long time. Already in the 1960s, disability became more acknowledged, mainly in educational and medical sciences. However, it was the change of power from Walter Ulbricht to Erich Honecker in 1971 that marked a tangible, arguably even the most pivotal turning point in the history of state welfare towards people with disabilities in the GDR. Testing these assumptions, this presentation wants to analyze, if this change on the political level actually translated into the everyday lives of people with disabilities. Embedded in a broader context of extension and intensification of social policy measures and based on foundations laid in the 1960s, the 1970s saw a notable increase in the attention given to the phenomenon of disability by the state that also impacted the private spheres of society. Here, care for and education of people with disabilities were among the realms particularly affected by the social policy changes under Honecker. Based on archival material produced by GDR officials, experts and private individuals and expanding on existing GDR disability history research (e.g. Boldorf and Barsch), the presentation aims to highlight concrete effects of the change of power in 1971 on these two, often linked, areas. Furthermore, the presentation wants to ask in how far 1971 can be understood as an actual caesura for GDR disability history in respect to care and education. By contrasting East German with West German policies, the presentation discusses if the changes in these areas attributed to 1971 – a typical caesura of GDR general and/or political history – can indeed be understood as specific to the GDR.

Keywords: caesuras and long term developments of European disability histories, international comparisons of European disability histories, care practices, special educational practices, transsystemic comparisons, Disability and time experiences

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*Speaker

"Inspiring true stories": Cripping up and the multilevel framing of disability in Breathe (2017) and Stronger (2017)

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Like other able-bodied actors before them, Jake Gyllenhaal and Andrew Garfield recently cripped up: Gyllenhaal played Jeff Baumann, double-amputee survivor of the Boston Marathon bombing in *Stronger* and Garfield starred as Robert Cavendish, a quadriplegic polio-survivor, in *Breathe*. Through a close reading of the two films this paper explores, how the socio-cultural practice of cripping up is comprised of cinematographic and discursive elements that let the viewer juxtapose 'disability' with 'normalcy' on both an intra- and an extra-diegetic level. Within the productions, make-up, cinematography, mise-en-scéne and CGI are used to frame the actors' able bodies as 'disabled,' allowing the audience to marvel at the transformation (Davis 2017). Films thus allow viewers to gaze at the disabled body without interruption, which resembles the scrutiny of the medical gaze (Mitchell/Snyder 2010). Since the characters in *Breathe* and *Stronger* only acquire their disabilities during the narrative, viewers can intra-diegetically compare the medicalized bodies of the newly disabled characters to their former, able-bodied selves. However, cripping up is also discursively bound up with the extra-diegetic processes of movie promotion and reception that further the contrast between the able-bodied actor and his disabled role. Because *Stronger* and *Breathe* are based on an "inspiring true story," audiences can also compare the actors' transformation to their real-life model. These overlapping processes of comparing and distancing help to underline the fictionality of the actor's disability that enables the audience to feel relief at the apparent "make-belief" of disability (Shinn 2014). Since cripping up furthers the perception of disability as an on-screen spectacle (Garland Thomson 2009) that has no room in real life, this paper analyzes not only the cinematographic framing but also the discursive creation of an actor's cripping up and the wider implications this has for the perception of disability beyond the movie screen.

Keywords: cripping up, film studies, staring, medicalization

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*Speaker

Healing, Haunting and Leaving Behind in Wolfgang Borchert's The Man Outside (1947)-Disability and Post WWII Western German National Identification

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Wolfgang Borchert's *The Man Outside* tells the story of disabled war veteran Beckman, who is searching for a home, care and relief from his guilt. Upon its release, the play served as a point of identification for numerous returnees who did not find their way back into society. My paper uses *The Man Outside* as a critical vehicle to explore the role of disabled veterans in Post WWII Western German national identification.

Even though the play is rich in depictions of disability, most analyses have left this aspect unaddressed. It seems as if disability is so plainly an illustration of the horrors of war that it is not worth mentioning. Drawing on the works of David T. Mitchell and Carol Poore, revisiting *The Man Outside* from a disability studies perspective goes beyond analyzing disability as means of social critique. Instead, my reading aims to accomplish a critique of the social construction of disability and its role in German national identification post WWII.

What can Borchert's play tell us about the post-war condition of disabled people and the role of disability in grappling with Germany's past? Taking into consideration intersections with normative constructions of heterosexuality and masculinity, my paper argues that politics of normalization and the lack of accountability for the horrors of the NS-regime are intertwined with the imperatives for war-torn body-minds to rehabilitate and reintegrate. Does disability emphasize the victimhood of Germans and thus foreclose taking up responsibility for the atrocities of the NS-regime? If the disabled cannot be neatly placed into rituals of remembrance as the dead can, do they serve as a disruption to dominant identity formation? Can different ways of dealing with the NS-regime lead to a "grappling with cure" (Clare 2017) which does not construct disability as needing to be overcome by any all means?

Keywords: heteronormativity, national identification, Heimat, Volkskörper, disability history, narrative prosthesis, rehabilitation

*Speaker

Albinism, Childhood And Global-Local Discourses in Tanzania

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This paper focus on the social construction of the "disabled child" in Tanzania. To do this I will consider the categories of "childhood" and "disability" - as areas of action variously defined by the different social actors- as well as on the relationship between these two categories and today's development policies. The issue of "albinism" is emblematic in this context. Indeed, Tanzanian albino activists struggle for the recognition of albinism as a disability, because being recognized as "disabled person" allowed them to obtain rights denied until then, as well as the recognition of the status of "human being".

The data used come from the participant observation and from semi-structured interviews with activists, teachers and tradicional doctors. Participant observation with children characterized the research. I needed to use alternative strategies to approach them, like the "incompetent adult" method, as described by Corsaro (2001), or the "taccuino condiviso" (shared notebook) by Nicoletta Sciarrino (2017).

The results show that:

- Sometimes the interpretative grids on which disability development projects are based are endorsed by the Tanzanian disabled community, which use them as a way to access treatment, protection and rights otherwise denied;

- Other times the meeting is more problematic, since ideologies, values and practices introduced by humanitarian workers and NGO clash with local ways of life.

Keywords: Disability, Childhood, Albinism, Tanzania, NGO

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[*]Speaker

When disability disqualifies. A vignette study of Danish employers' attitudes toward persons with physical disabilities

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Today, most European societies are facing the important task of improving the labour market situation for persons with disabilities. In this respect, employers play a key role. Previous studies have been engaged in employer attitudes in order to discover factors influencing their decision whether or not to hire persons with disabilities. However, reluctance toward disabled people may overstep norms of tolerance and inclusion, affecting employers' inclination to give honest answers.
To obtain a realistic picture of employers' intentions and motivations for hiring people with disabilities, this study applies a factorial survey experiment with vignettes among Danish employers. The vignettes are brief descriptions of a potential job candidate, where one group of respondents receive additional information on the candidate being physically disabled. Subsequently, respondents answered how likely it would be for them to hire the person. To test presumed motivational factors, we added information on economic compensation schemes for yet a group of respondents, and a recommendation from the local job centre for another.

The results clearly demonstrate that employers are reluctant toward hiring a physically disabled person. When exposed to the vignette with a disabled candidate only 21 per cent are likely or very likely to hire, as opposed to 70 per cent of those exposed to the impliedly able-bodied candidate. Neither economic compensation nor job centre recommendation tend to incentivise hiring.

Overall, the findings suggest that disability in itself is disqualifying for the candidate in the hiring process. Theoretically, the findings are interpreted by the concept of aversive disablism which describes unconscious prejudices and offers an explanation of employers' ambiguity and of why motivational factors do not influence the inclination to hire a disabled person.
Through the experimental design we bring novel knowledge on the magnitude of employers' reluctance toward disabled employees and shed light on the reasons why.

Keywords: Physical disability, employment, factorial survey, vignette

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The "New Socialist Invalid": The Self-presentation of People with physical Disabilities in early-socialist Czechoslovakia (1945–1955)

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The unprecedented political and social changes in Czechoslovakia after the WW2 brought an undisputable improvement of the living conditions for the physically disabled. However, more important was a great shift in their identity, as the concept of "new socialist invalid" emerged. In contrast with the "old invalids", who had been presented as the products of unjust social conditions of the past and mere passive receivers of charity, socialism had supposedly brought people with physical disabilities a true emancipation. Seen through the collectivist ethos of social usefulness, they lost their "invalidity" when they joined the process of building socialism. Moreover, the "new invalid" became a symbol of the humane nature of the regime and also a central figure in the peace movement: a living evidence of the horrors of "imperialist" wars. The one-sided interpretation presented above should be critically deconstructed. Under the umbrella identity of "new invalid", various sub-identities based on particular disabilities, with specific and sometimes even contradicting interests, still persisted. How was the symbol "new invalid" produced in this situation? Which specifics were successfully incorporated, and which left aside? Who was the right "new invalid"? The case of Czechoslovak war invalids should be noted, as they had lost their organization and gradually merited legal status, could be interpreted as a result of them not being compatible with the "new invalidity" concept. Finally: Did the concept contribute truly new ideas and impulses to the (self-)perception of the disabled and were the elements of socialist ideology much different from the past or from a capitalist approach? Had the disabled been publicly recognized according to the new invalid concept or was it rather a symbol? To answer the questions, different publications and periodicals as well as public performances of the Association of the Czechoslovak Disabled and state and party institutions are analyzed.

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*Speaker

Technomediation: Music Hearing with Cochlear Implants

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In our talk, we present the results of a media ethnographic study on music hearing practices with cochlear implants (CI) conducted in cooperation with the CI-Center in Freiburg, Germany. We departed from the idea that in contemporary society music is ubiquitary, it gives access to different forms of experiencing and purchasing knowledge, and enables us to take part in social live. The ability of hearing is an equally necessary and unreflected condition. Music challenges deaf or hard-of-hearing persons, and they respond in different ways like sign language, sign dancers, visual jockeys or, a technical solution, the CI. By transmitting incoming acoustic signals to the brain the neuroprosthesis opens interfacing processes between medical technology, audiology, media studies and music or music therapy that are not only of direct use for CI-listeners, but also call for interdisciplinary research projects.

While most medical studies or audiological trainings aim at standardizing and normalizing hearing, our project departed from the premise that CI-hearing practices are part of an interactive process of subjectivation and socialization in and through which technical, medical and socio-cultural decisions and experiences are intertwined. We focused on CI-hearing practices with different music devices, in diverse situations and environments that, partly, cause the transformation of the CI from a therapeutical instrument to a life style product. We elucidated the complex processes of CI-hearing, (hearing) control and self-control, asymmetric power relations, possibilities of deliberately ignoring (not-listening), as well as individual descriptions of affecting and being affected by hearing music with CI. Methodologically we conducted our research by making use of (video)ethnographical tools, questionnaires and standardized interviews, which in a second step were framed by actual theories of dismediation (Mills/Sterne2017) and methods of STS (Schillmeier 2010).

Mills,Mara; Sterne,Jonathan.2017. Dis-mediation In: Ellcessor, Elizabeth. et.al., eds.Disability media studies. NY:: NY UP, 365-378.
Schillmeier, Michael. 2010..Rethinking disability.NY: Routledge.

Keywords: Cochlear Implant, CI, music, listening to music, meda enthography, STS, Science and Technology Studies, hearing, non, hearing, deaf, knowledge, enabling, disabling

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*Speaker

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How assistive app arrangements enact dis-/abilities and sensory practices

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Our daily, socio-material practices (Mol2002) are increasingly enacted through the entanglement of people, digital technologies and complex infrastructures. Smartphones, other mobile devices and apps are becoming ubiquitous (Wade/Murray2018). They complement and challenge established forms of mobilities, communication and sensory modalities. It is a critical moment, where the question is raised of how digital technologies can be accessed and in which ways they facilitate or inhibit forms of cultural and societal participation (Ellcessor2016). This also relates to a tension between prescriptive assistive technologies, over-the-counter mainstream technologies and assistive apps.

Against this background, my presentation starts with an overview of current mobility apps for visually impaired and blind people (Blindsquare, Soundscape) and then analyzes how contemporary sensory practices are re-configured by assistive app arrangements. By referring to Schillmeier (2010:138) and Mol (2002:33), I argue that sensory practices and dis-/abilities are enacted by heterogeneous (non-)human actors. This enactment is situated in events where user and the environment are produced reciprocally and simultaneously. I consider selected applications – Camassia (2018) and The vOICe (since 1992) – that use sonification (Supper2012) to render information on the surroundings hearable showing how auditory practices, sonic skills and acoustic spaces are interlaced.

This presentation is part of a postdoc research where I analyze dis-/abling practices, music, sound and digital technologies and how they shape processes of in- and exclusion. It will draw on diverse materials (TV and other advertisements, scientific articles and newspaper articles). Particular emphasis is put on app reviews by blind users on blogs, in online forums or video sharing platforms. Expert interviews with blind app users are also planned. For the analysis of my material I use extended discourse analysis, film analysis and qualitative interview analysis. My interdisciplinary inquiry connects the currently emerging media disability studies (Ellcessor/Kirkpatrick2017) with the field of sound studies (Bull2018; Friedner/Helmreich2012).

Keywords: assistive technology, accessibility, dis/ability, techno/sensory modalities, socio/material practices, apps for blind and visually impaired people, sonification

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[*]Speaker

Lifelong guidance alternatives for young disabled persons in Hungary

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1, Károly Tóth *

1, Dániel Csángó *

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Supporting lifelong learning of young disabled persons, developing lifelong guidance methodological knowledge, expanding networks and service portfolio are strategic questions of the past fifteen years in the European Union and play a central role in shaping national policies. At the same time, according to the ILO and OECD reports, persons with disabilities are very disadvantaged in the labor market as regards the transition from secondary education, job search and long-term career building (ILO, 2014, Ebersold, 2012).
The Carry On! research with its qualitative orientation is a question-driven, participatory study, aims to map the Hungarian lifelong guidance and future planning practice available for disabled persons in different school structures and highlights their experiences. According to the participatory approach, we consider it important that disabled persons should not only participate in the process as a target group, but also as active co-researchers. In this type of research, scientifically acquired knowledge and insider experience are mutually supportive (French, Swain, 2004; van der Riet, Boettiger, 2009). Novelty of the project is, that we particularly focus on the experiences of persons with high support needs and their allies. Our research can be interpreted in the disciplinary context of Disability Studies, but it also uses the literature base of social sciences and boundaries.
We interviewed young disabled persons, their families and the actors in the institutional system about their experiences with the current guidance practice. Focus group interviews, individual semi-structured interviews have provided an opportunity to present the strengths and areas to be developed, and to reflect on common opportunities and threats. Individual life-interviews, complemented with timeline method, have provided a more accurate picture on the experiences.

Keywords: participatory research, disability studies, lifelong guidance, persons with high support needs

*Speaker
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Including disabled people in society: a matter of legal rights or a matter of costs?

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This paper presents a study about the claims of disability activists in contemporary Sweden. This Scandinavian country is an interesting case because, although Sweden is often praised for its generous welfare system and although it has ratified the UNCRPD and adopted ambitious strategies for disability politics, very little is known with regard to the claims raised by its citizens who engage in the public sphere around the issue of disability.

The empirical data consists of 312 blogposts and 163 debate articles that were published in the Swedish public sphere over the past decade. A content analysis was performed on these data, based on the following question: What are the claims of the Swedish disability activists about, i.e. what problems do they raise and what solutions do they propose?

The paper argues that the Swedish disability activists' claims can be understood as a struggle for citizenship and shows that the activists resist unequal opportunities, exclusion and domination, and demand participation, equality and the guarantee of the basic interests of disabled people. The paper then calls attention to the tensions and dilemmas underpinning the activists' claims and in particular to the tensions and dilemmas revolving around the issue of legal rights and costs, which are mentioned in 53% and 42% of the data respectively. The paper presents the different ways in which the activists mention costs and legal rights and discusses these empirical findings in light of the academic debates concerning the uneasy relationship between civil and social rights on the one hand, and between claims of recognition and redistribution on the other hand.

Keywords: disability, activism, Sweden, citizenship

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[*]Speaker

Confusing Circumstances Surrounding Deinstitutionalization and Inclusion in Japan

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The aim of this report is to examine efforts towards deinstitutionalization of disabled persons to live in the community in Japan. To that end, I will report the incident on 26 July, 2016 that 19 disabled people were killed at a large residential facility by a former employee in Japan ("Sagamihara stabbings"), reviewing the background of the incident and analyzing the discussion process with regard to coping with the facility and its residents in the future.

Data used for this report are; newspaper reports about the incident, statements made by disabled peoples' organizations (DPOs) regarding the incident and the policies of local government the facility was located, records of the discussion by the task force established by the local government on the policy for dealing with the facility and its residents in the future.

The results are as follows;

After the incident, the governor of the local government announced that a same type of residential facility would be totally rebuilt at the same location, as requested by the families of the residents. However, there was a great deal of criticism from DPOs and disability policy experts, who claimed that large residential facilities had become anachronisms and smaller-sized, community-based living arrangements had become the international standard. The governor was forced to change the policy.

One of the underlying reasons of this confusion is a chronic lack of welfare services for the disabled person to live in the community, especially in the area of personal assistance. The situation is such that family members of the disabled person have to bear burden of care, and crave for a conventional type of residential facility for his/her/their security. I will point out the responsibility of the Japanese government to improve coordination of community resources for disabled persons under the Article 19 of the UN CRPD.

Keywords: Deinstitutionalization, Inclusion, Japan, Disabled Peoples' Organization (DPO), UN Convention

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Child and adolescent conduct disorder/psychopathy" controversies in post-colonial France: The legacy of a 2005 public health scandal that remains a heated affair

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In 2005, the National Institute of Health and Medical Research (Inserm) published a report entitled on "Child and Youth Conduct Disorder". The already controversial document became the subject of general critique in 2006 when it was cited by the then interior minister Nicolas Sarkozy cited in reference to "today's black giants from the periphery who are under eighteen and who frighten everyone".

Dialogues were initiated in four different "spaces" in order to understand the implications of this ongoing affair over an officially recognized "handicap" in France since 2005: (1) The written and oral debates of the "Pas de 0 conduite" [No Zero for conduct] movement uniting early childhoood "risk-prevention" professionals concerned about the "law and order" implications of the controversial report. (2) The multidisciplinary workshops on "Behavior Disorders" The National Instituted on School Disabilities and Adapted Education (INSHEA). (3) The school settings of several students categorized "behavior disordered" in urban zones with histories of Subsaharan and North African immigration as well as from a rural working class zone with negligible non-European immigration. (4) Outreach programs and cultural debates between professionals within the French and Brazilian hip-hop movement working with anti-"at-risk" youth in the same post-colonial urban zones.

Anglophone critical disability studies were used to generate dialogue in each space and the results were integrated into a broader framework thanks to "scandal" and "controversy" analysis tools from French pragmatic sociology. With the help of grounded theory content analysis, this research presentation will analyze the common themes that emerged in the dialogues in these four different spaces. By examining the mutual critical positions of each space and of the 2005 research on "youth and child conduct disorder", the multidisciplinary results can contribute to a constructive resolution of this ongoing controversy.

Keywords: Conduct Disorder, Psychopathy, Delinquency, Stigmatisation, Post, colonial immigration

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*Speaker

Social adjustent challenges for parents of physical handicaped children in Pakistan

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Social adjustment of physical handicapped children is challenging for parents. It is comprised of dignified interaction between persons with disability (PWD) and without disability, participation of person with disability in different communal and social practices. Societal attitudes of persons without disability towards PWD vary according to types of severity they have. This difference in attitude becomes a significant factor that clandestine affects socialization process of PWD particularly their social adjustment. This study was designed to explore the attitude of parents towards social adjustment of PWD. This study was quantitative in nature and survey design was adopted. Convenient sampling technique was used to collect data. Parents of physically handicapped children of district Bhakar; a small city of a province 'Punjab', Pakistan, was population of this study. Statistical tests were employed to find the significant differences based on some demographic variables. Analysis of data received from participants showed that parents of physically handicapped children showed that parents want their children full social adjustment. Secondly, it is found that parents are facing various problems like social acceptance of their children, participation, free mobility, and stigmatization regarding social adjustment. Our study found that there is no significant difference in the mean score of attitude with respect to various demographic variables. Further, parents face various difficulties in social adjustment of their children for example, in dignified interaction, and as far as participation in the different communal and social practices are concerned.

Keywords: parents, social adjustment, physically handicapped, stigmatization

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*Speaker

The institutionalised lives of persons with profound intellectual disability: Considerations from an ethnographic study

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[1] Stockholm University – Sweden
[2] University of Helsinki – Finland

In this presentation, we will analyse some key findings from an ethnographic research project *Profound Intellectual and Multiple Disabilities and a Good Life* (funded by the Academy of Finland, 2014-2018). The project's data was produced by following the everyday lives of six adults with profound intellectual and multiple disabilities (PIMD). Ethnographic fieldwork was carried out during 2015-2016 in everyday contexts of the research participants, including day centers and housing units providing services for people with PIMD in Southern Finland. Each participant was followed for a period of 3 to 4 months. The research data consists of ethnographic field notes, interviews of family members and care workers, and written documents concerning the care and services provided for the research participants.

We discovered that a good life materializes only in a very limited sense in the everyday lives of our research participants. This is because they live very institutionalised and socially isolated lives. Their lives are encompassed within and are dictated by the disability service system with the result that they live non-individualised and non-personalised lives.

This group of people is largely ignored in disability studies. The materialist and cultural approaches in the field fail to do justice to the lived experiences of disability where impairment effects are insurmountable. Therefore, in the end we will reflect upon appropriate ways to engage theoretically and ethically with the lives of persons with PIMD.

Keywords: profound intellectual disability, ethnography

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Bridging Gaps through Photo-Acoustical Montage

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Part art and part empowerment, this presentation illustrates one way to bridge communication gaps about space and place between blindness and sight. There are many ways that people communicate with one another, but when it comes to blindness, particularly for persons born blind, visual ways of communicating seem to be out of reach. Yet, by capturing the sighted world through human senses other than sight while using a camera, blind photography supports communication beyond the verbal. That is, blind photography is known to capture experiences that are both the same and different from photography by persons with sight where, for example, acoustics and materiality are captured through still visual images that show a moment in time within a specific place. For instance, the underside of a stone bridge can illustrate the space as being oppressive, dark, heavy, and with a closed sound. This presentation takes blind photography a step further by adding acoustical soundscapes to create montages that communicate even more deeply about space, place, materials and sound. The photo-acoustical montage brings together embodied experiences that speak to both blindness and sight in profound ways about everyday and exceptional experiences. Author one, who was born blind, creates photo-acoustical montages to bridge gaps about the sighted world to share with friends (and family) such as author two. This presentation includes a dynamic photo-acoustical montage created by author one and a discussion about how this art form bridges communication gaps in extraordinary ways.

Keywords: blindness, blind photography, communication, empowerment, soundscape

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*Speaker

Conference Opening and Host on behalf of ALTER

Isabelle Ville [*] [1]

[1] School for advanced studies in social sciences (EHESS) – Ecole des Hautes Etudes en Sciences Sociales (EHESS) – France

Today, disability is understood as a multidimensional phenomenon, specific construction, and multifaceted field of research that is researched internationally, comparatively and across disciplines. In Germany, Disability Studies is a relatively young field of research. In international and European countries, on the other hand, there is a longer, extremely diverse research tradition. For the first time in German-speaking countries, ALTER, the European Society for Disability Research, based in Paris, is organising its 8th Annual Conference 2019 at the University of Cologne.
The conference entitled, "Histories, Practices and Policies of Disability" is hosted by:

Prof. Anne Waldschmidt and Curie Lee (International Research Unit in Disability Studies - iDiS, University of Cologne) and
Prof. Matthias Otten(TH Köln – University of Applied Sciences) and
Prof. Isabelle Ville (École des Hautes Études en Sciences Sociales - EHESS, Paris).

ALTER is both a learned society and a peer-reviewed journal (European Journal of Disability Research) dedicated to the research of disability and otherness. While it is based in Europe, both the society and journal are open to the international scientific community and all respective stakeholders (students, teachers, people with disabilities, policymakers, disability organizations, etc...). For more information on ALTER, including past conferences, you may visit their website here: http://alter-asso.org/

The 2019 conference is the 8th in the series of ALTER conferences and aims to contribute to the thriving discourse of international, comparative and transdisciplinary disability research. It offers a platform for debates and conversations between regions, disciplines and theoretical perspectives. It presents an opportunity for exchange between young scholars and senior researchers in disability research and critical disability studies.

Keywords: Disability Research, Europe

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[*]Speaker

Conference Opening and Host on behalf of University of Cologne and iDiS

Anne Waldschmidt *† 1, Curie Lee * ‡ 2

1 University of Cologne – Germany
2 University of Cologne – Germany

Today, disability is understood as a multidimensional phenomenon, specific construction, and multifaceted field of research that is researched internationally, comparatively and across disciplines. In Germany, Disability Studies is a relatively young field of research. In international and European countries, on the other hand, there is a longer, extremely diverse research tradition. For the first time in German-speaking countries, ALTER, the European Society for Disability Research, based in Paris, is organising its 8th Annual Conference 2019 at the University of Cologne.

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Prof. Isabelle Ville (Ecole des Hautes Études en Sciences Sociales - EHESS, Paris)

About the University of Cologne (UoC) and the International Research Unit in Disability Studies (iDiS)

The UoC was founded in 1388 and, since then, has become a hub of research and scholarship in Europe. It is considered one of the largest German universities, alongside Free University of Berlin and the University of Munich, and is one of the leading research universities in Germany as it won funding for four excellence clusters through the Excellence Initiative launched by the German federal and state governments to support outstanding projects and institutions at German universities. The UoC is a full university with six faculties covering a broad spectrum of disciplines and offering many internationally outstanding research profile areas. The life and natural sciences are represented by the Faculty of Medicine and the Faculty of Mathematics and Natural Sciences. The Faculty of Management, Economics and Social Sciences and the Faculty of Law both enjoy an excellent reputation in application-oriented research and are regarded as top German institutions in their fi elds. The Faculty of Arts and Humanities builds on a comprehensive and broad range of disciplines and has developed many successful research areas, e.g. in pre-modern cultures, medieval studies, literary studies and non-European cultures and languages in general and Africa research and cross-linguistic research in particular. The Faculty of Human Sciences was founded in 2007 and has already established successful research areas in, e.g., intercultural education and social psychology. In addition, its Department of Special Education and Rehabilitation is one of the largest centres in Europe.
Affiliated to the Faculty of Human Sciences is iDiS. This research centre was founded in 2004 by Professor Anne Waldschmidt and has been the first of its kind in disability studies in German-speaking countries. The iDiS is dedicated to critical disability studies and internationally

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renowned for producing interdisciplinary research on disability that combines social sciences approaches with cultural studies. Over the last years, the iDiS has undertaken a number of major research projects that have resulted in numerous publications, workshops and lectures. Third-party-funded projects at the iDiS have so far dealt with the following research areas: an international comparison of disability policies, equal rights and accessibility as well as disability history, bioethics, sociology of knowledge, and body theory. The centre is involved in the teaching of BA and MA students of (special) education and rehabilitation sciences and holds regular research colloquia for Ph.D. students.

A socio-technical history of the ultra lightweight wheelchair

Nick Watson * [1], Hilary Stewart

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The wheelchair represents the single most important technological advance in the development of technology for millions of disabled people throughout the world. The ultralightweight wheelchair, which emerged in the post-war years is, for many, the highpoint in technological innovation. It saw the weight of a wheelchair fall from around 50 kilos to around 8 kilos and opened up new possibilities for wheelchair users. Designed mainly by the wheelchair users themselves, often against the wishes of professionals and manufacturers, and driven by their desire initially to improve their sports performance and later by their wish for wider access to the community and the built environment. Its emergence represented a new trajectory in wheelchair design, one that not only improved the technology but also was part a revolution in wheelchair manufacture, prescription use, disability politics and identity. The development and evolution of the modern wheelchair has occurred at the same time as the liberation of disabled people. Its effects on the development of disability politics has, to a large extent, been ignored. In this paper, using methods developed in both disability studies and the social construction of technology, in particualr the idea of boundary objectsm we chart and document the emergence of these wheelchairs. It is not a linear history, it's a very complicated picture, with the ultra lightweight emerging out of the interaction of different actors and actions, some of them planned, some of them unforeseen.

Keywords: wheelchair, history of disability, disability sport

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*Speaker

Psychiatry during Nazi rule - My Grandmother died in psychiatric clinic in Göppingen in 1945

Jörg Watzinger * [1]

[1] none – none, Germany

My grandmother, born 1880, died in May 1945 in the psychiatric clinic Christophsbad in Göppingen/Germany. My father, born 1913, was imprisioned for political reasons from 1939 to 1941. After returning home he was deported to concentration camp Dachau for 3 years. He survived.
My grandmother got mad of despair and went to psychiatric clinic in 1942 where she died in May 1945.

My presentation will look for anwsers to the question whether her death was an effect of Nazi ideology. What meant Nazi ideology to psychiatry and psychotherapy in Göppingen.

My interest is to show what changed in pychiatry during Nazi rule. Would my grandmother have survived her madness before or after Nazi rule.

Since several years I follow up the fate of my father's KZ imprisonment and Nazi politics. Since 2 years I take part in groups of decendants of Nazi persecution and I am engaged in starting new groups. Now my topic is psychiatry during Nazi rule.

Online publications on my father and my grandmother
https://reflections.news/de/fuer-ein-gerechteres-demokratisches-deutschland/
https://reflections.news/de/grossmutter-marie/

Keywords: psychiatry, effects of nazi ideology in psychiatry

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*Speaker

To Be Continued? - Serializing Traditions of Cripping up on American Television

Gesine Wegner * [1]

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Considering the long history of "disabled/disabling images" (Gartner & Joe 1986) on American television, this paper sheds light on ableist practices of exclusion and marginalization that permeate the popular medium up until today. While failures to include disability communities in the creative process of TV-making are increasingly addressed by critics on- and offline (Haller 2018), not much seems to have changed about how and by whom disability is represented on the small screen. Among others, the practice of cripping up – the portrayal of a disabled character by a non-disabled performer (O'Reilly 2011) – has seen a new uplift in highly popular shows like Grey's Anatomy and The Big Bang Theory. The cultural influence that these prime-time shows continue to wield worldwide makes them particularly interesting to scholars in cultural studies and disability studies. Reaching millions of viewers every week and over a period of several years, American television shows shape popular discourses on disability unlike few other (non-)fictional formats. Yet, although nearly one in five citizens in the US have a disability (Brault 2012), people with disabilities make up only 2.1 percent of regular characters shown on prime-time television in the current 2018–2019 season (GLAAD 2018). With disabled characters being unquestionably few in number, what does it mean, though, for audiences to encounter these characters mainly as they are portrayed by non-disabled performers? My paper will illustrate that practices of cripping up have depleting effects on representations of disability in serialized narratives. I propose that television holds much potential for portraying disability in a more complex fashion than other media. At the same time, this potential remains frequently unrealized due to a reliance on the cinematographic effects and affects that are created by more traditional negotiations of disability.

Keywords: Cultural Disability Studies, Television Studies, Cripping up, Representation

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*Speaker

Technology's Impact on Tasks of Employees with Disabilities in Germany (2006-2017)

Sabrina Weller * [1]

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New technologies and new working requirements result in changes in employees' task composition. According to the Routinization hypothesis, the increasing use of computer technologies in the workplace is leading to a complementary of non-routine (analytic and interactive) tasks and substitution of routine (manual and cognitive) tasks (Autor et al. 2003; Goos & Manning 2007). We examine the effects of the technological change on the tasks of employees with disabilities between 2006 and 2017.

We assume that persons with disabilities are at a disadvantage in the changing world of work due to the lower number of highly qualified disabled persons and because increasing computerisation does not inevitably lead to the utilisation of high-tech equipment that simplifies the work of physically impaired persons (Engels 2016, Weller 2017).

We use representative data form the German BIBB/BAuA Employment Surveys 2006 and 2017, where 20,000 gainfully employed people were asked about their Qualification and Working Conditions. We run separate regression models for employees with and without a certified disability in the years 2006 and 2017, where we analyse the influence of computer usage (independent variables) on different task categories.

Keywords: Digitalization, TASKS, inclusion, disability

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*Speaker

First results on normality and disability in sibling relationships

Carla Wesselmann * [1], Clarissa Schallenberger *

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The WINDIS study (**w**hat **is n**ormal – **dis**abled?) 2018-2020 focuses on how normality and disability are experienced and constructed across the life course (Priestley 2003) of siblings older than 45 years. The phenomenon disability serves as a heuristic instrument (Waldschmidt 2005) to examine individual, familial and social ideas about normality. With a biographical approach and data collection through narrative interviews (Schütze 1977), the study aims to explore strategies of (self-) normalization and labeling of difference with regard to underlying normative references. That means the study does not differentiate into individual types of disability. Therefore, the first wave of surveys includes biographical narrative interviews with 4 differently disabled and 4 non-disabled siblings. These interviews are going to be evaluated according to Rosenthal (1995) and Miethe (2014). The question however is: is it legitimate that peer researcher evaluate the interviews without the interviewees and then have the results validated through group discussion? In this talk both authors of the peer research are going to present their field experiences on basis of two welcoming and interaction rituals that irritated their normality ideas and those of their interviewees.This is going to be followed by the presentation of the first results of their cases with a view to the question of the construction of (self-) normality and difference.

Keywords: Peer research, Normality, Disability, biographical approach & narrative methods, interaction rituals

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*Speaker

Auto-assistive bodily practices. A history of early haptic technologies and practices

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The proposed contribution takes a media-archaeological approach and investigates into the "hearing glove" and the succeeding project "FEELIES"/"Felix" at MIT Research Laboratory of Electronics (RLE) between 1948 and 1951. This vibrotactile apparatus transformed sound into palpable signals, sent to the user's fingertips through a vibrating diaphragm. It was designed by Norbert Wiener and Leon Levine and intended to assist persons who were deaf or hard-of-hearing.

The scholar Helen Keller and Leo Sablosky, a man who lived nearby RLE, both deaf-blind, contributed to the development (Mills2011). Not only did Keller and Sablosky participate in testing sessions. Also, both – long before becoming involved in the work at RLE – already used a similar "technique" when touching their opposite's lips/throat/chest in face-to-face conversation to feel their voices' vibration (Keller1929; Mills2011). As highlighted by Mills (2011), insights offered by persons with disabilities were – and still are – of fundamental importance to research in "prosthetic technologies". Adopting Mill's approach, I will illustrate how the hearing glove produces a *tactile practice* revealing an inherent material potential of the body to assist itself, to become its own "prosthesis". Consequently, I would like to put forward that:

I) it is particularly the sense of touch which holds these *self-sufficient potentials*

II) these *auto-assistive bodily practices* usually reveal themselves in interactions aiming to facilitate communication between "non-disabled" and "disabled" people and, thus, may be considered *acts of translation.*

Finally, these insights are read against the backdrop of today's digital haptic feedback experiences (see Parisi2018; Harrasser2017).

Keywords: assistive technology, accessibility, dis/ability, techno/sensory modalities, socio/material practices, Cochlear Implant, haptic technologies, apps for blind and visually impaired people

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*Speaker

Performing disability, cripping the theater: Cripping up and the re-entry of the disabled artist on stage

Noa Winter * [1]

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In recent years, cripping up, the portrayal of a disabled character by a non-disabled performer, became an increasingly virulent subject in public and scholarly discussions about the representation of marginalized people in film and television (Davis 2017). Nonetheless, the phenomenon is still rarely discussed when it comes to theater productions (O'Reilly 2018). Thus, my talk will shift the perspective from acting on screen to acting live on stage to explore how the cultural practice of cripping up changes with the formats in which it is applied. For example, the analysis of a theater performance needs to consider not only the highly normative training of acting techniques that Carrie Sandahl calls "the tyranny of neutral" (2009) but also the representation of disability in a situation where spectators and performers are co-present (Siebers 2010; Fischer-Lichte 2004). This co-presence significantly influences the politics of staring (Garland-Thomson 2009) and the conception of disability as an "exotic spectacle" (Mitchell/Snyder 2010) on stage. Finally, following Fox and Sandahl's notion to go "beyond cripping up" (2018), my talk will shed light on the largely undiscovered potential of theater and drama for disability studies by contrasting the cultural practice of cripping up with the re-entry of the disabled artist in two recent productions: the premiere of Katie O'Reilly's Shakespeare adaption richard iii redux OR Sara Beer [is/not] richard iii by The Llanarth Group and the staging of Samuel Beckett's Not I by the London-based company Touretteshero.

Keywords: Theater, Cripping, Arts, Performance, Drama, Representation

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*Speaker

Disability activists in the struggle for independent lives, equal opportunities and human rights in Poland. On the power of the protests, the government's oppression and social defiance.

Agnieszka Woynarowska * 1

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In April 2018, the disability activists of the social movement: The Parents of Children With Disabilities, began a sit-in protest in the Polish Parliament, the largest one in the history of contemporary Poland. In their postulates they demanded the current government to take immediate legislative action that would aid the people with disabilities to lead dignified, independent lives. The protest, which became a new form of political action by the activists with disabilities, and which caused new actors to emerge on the public scene, who would demand the right to have rights, initiated an entire array of political and social reactions. One could say, that it put the Polish society and the Polish state to a test. In my paper, I will present the results of the critical discourse analysis of the protest itself: the discourse of politicians, the discourse of social policies, the discourse of the activists and the social discourse. I would like to present answer to the question: within what discourses and social practicies the protest was held? The presented analysis will shed light on the paternalism of the government, discover the biopolitical technologies of ruling the body, pushing people with disabilities into the background of social life. Moreover, it will show the mechanisms of control, oppression and discrimination of people with disabilities, that manifest within the practices of exclusion, aggression, disinformation, ignorance, or isolation. In my paper, showing the discourse of the protest will serve as background and a starting point for presenting the social activism of people with disabilities, as well as, social revolutions led by disability-rights activists in Poland. Moreover, the aim of the presentation is to show, how the disability policy is shaped in the context of the aforementioned revolutions, and sketch out the attitude of the government towards disabled citizens.

Keywords: disability activists, human rights, equal opportunities, disability rights movements

*Speaker

Unknown disability histories and the Soviet past: the Action Group case

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The paper presents the undeservingly forgotten story of the Soviet Action Group for the Defense of People with Disabilities Rights. Founded in 1978 inside the broader soviet dissident movement, the Action Group launched the human rights bulletin and organized the far-reaching mail network with people with disabilities' responds from all former Soviet Republics. Mails contained life stories and particular cases of rights' abuse as far as fulfilled questionnaires with detailed information about disability status, life conditions, family, employment, mobility and participation in social life.

The analysis of the case is built mainly on the archival research of the Group documents and personal papers preserved in the archive based in the International Historical Society "Memorial" in Moscow. We also conducted a couple of semi-structured interviews with Group's ex-members and supporters, who enriched the narratives we gained from the archive work.

The Action Group portrayed the unspoken issues and challenged the concept of USSR as a state of social justice and ubiquitous equality. Inevitably it led to harsh government counteractions and repressions, due to which the Group fell apart in 1983. Applying the concept "the politics of disability" (Oliver, Zarb, 1989; Iarskaya-Smirnova, Romanov, 1990) it is possible to treat the Action Group campaigns as one of the first grassroots movements in the former USSR, which shaped the nature of the broader human rights movement and citizenship of people with disabilities as far as the developments of social policy in modern post soviet countries.

Keywords: soviet dissidents, human rights, disability histories, samizdat, grassroots initiatives

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Time, Otherwise

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When considering places, spaces and time-including human performances, dynamics of movement, and the multitude of ever changing human and nonhuman actors entangled within spaces-these are highly complex even without the concept of 'disability time'. By conjoining disability time with explorations into the built environment, we begin to see the experience of time, otherwise. But what is disability time? Is it a concept that has traction? And if so, what are the societal and cultural implications? Perhaps disability time is about performances of taskscapes within the built environment through the lived experiences and abilities of people? Perhaps it is only based in the practical elements of 'how much time something takes'? This presentation explores the concept of disability time (which is not necessarily linked to disability alone) that offers less normative ways of considering time. This exploration is framed by complementary theories on material culture and disability studies and is fleshed out through nearly two decades of ethnographic research into urban place, spaces, and people's everyday movements in Europe, North America and China. The ethnographic research involved deep analysis of artifacts of the built environment with hundreds of participants towards better understanding their embodied know-how. Various techniques such as dialoguing while in motion, talking whilst walking and participants capturing video/photos were used. The resulting rich narratives and observations illustrate various aspects of the heterogeneity of disability time that questions naïve assumptions about time as a universal concept. Themes explored in relation to disability time include: navigating, mapping and memories of space and place; encountering and managing shifts in the urban landscape; and interactions with human and nonhuman actors within space and place. This is a multi-media presentation that is part poetry and part film that illustrates and questions the experience of place, space and movements through disability time.

Keywords: ability, built environment, disability time, lived experience, performance

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[*]Speaker

Seeing, Vision, the Body and Public Art: Experiencing Culture in the City

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The act of seeing is typically thought of as something that people are taught through observation, theories on visual perceptions, and/or the language of design. Yet, having vision and being taught how to see does not necessarily equate to really seeing that which is detailed and complex. This presentation moves beyond seeing with the eyes to explore how people see with their bodies, through an embodied approach, when confronted with public art. We believe that public art has the potential to transform experiences within cities, particularly for persons with disabilities, and this work is linked to previous research on blindness and multisensoriality. This presentation looks at art in public spaces and it's potential to inspire seeing with the body, which includes opportunities for persons with disabilities. Numerous pieces of public art were studied within public spaces including art on street corners, in airports, in bus terminals, and in libraries. Types of art are sculptures, furniture, and monuments, which are inherently contextual (e.g., including other objects, spatiality, natural materials, human-made materials) and are encountered and/or experienced by people in dynamic and fluid ways that involve seasonal and daily conditions, temporality, are indoors and outdoors, and more. To get at actions of embodiment within public spaces we use observational methods that reveal less routine and controlled engagements of people therefore getting at naturally occurring movements and behaviours with the public art. This natural and seemingly unconscious way of engaging reveals nuanced levels of attachment, preferences, taste and ways of seeing that show a deep connection to a body-knowing. Our results tell a story of how when codes of behaviours are removed, dynamic interactions, multiple interpretations and performances occur with and around public spaces creating opportunities for engagements and reflections that are not otherwise possible.

Keywords: ability, complexity, blindness, embodiment, interaction, multisensoriality

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Country characteristics and the disability employment gap

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Despite the UN declaration on the Rights of Persons with Disabilities, the labour market participation of persons with a disability remains lower than that of persons without a disability, i.e. there is a disability employment gap. This research examines the disability employment gap for men and women separately and tests whether ratification of the CRPD has had an influence on the disability employment gap. Moreover, it tests the influence of labour market characteristics on the disability employment gap and presents a new theoretical perspective. Focusing on a cultural explanation, it examines if disability rates are affected by attitudes towards disabled people. If less people report that they are hampered by a disability in countries with more negative attitudes towards disabled people, this may be an additional explanation for differences in the disability employment gap between EU countries. Using the EU-SILC, the results show that Southern-European countries have the smallest disability employment gap, but that ratification of the CRPD did not increase the probability to have paid work for those with a disability. Moreover, whereas stricter employment protection legislation is beneficial for people with disabilities on the labour market, other labour market policies specifically relevant for this group do not affect their chances on the labour market. We do not find an influence of attitudes towards disabled people either.
References

Baumberg, B., Jones, M., & Wass, V. (2015). Disability prevalence and disability-related employment gaps in the UK 1998-2012: Different trends in different surveys? *Social Science and Medicine*, *141*, 72–81.

Geiger, B., Van Der Wel, K., & Tøge, A. (2017). Success and failure in narrowing the disability employment gap: Comparing levels and trends across Europe 2002-2014. *BMC Public Health*, *17*(1), 1–7.

Keywords: Disability employment gap, atttiudes towards disabled people, ESS, LFS

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