Abstracts for workshops and symposiums
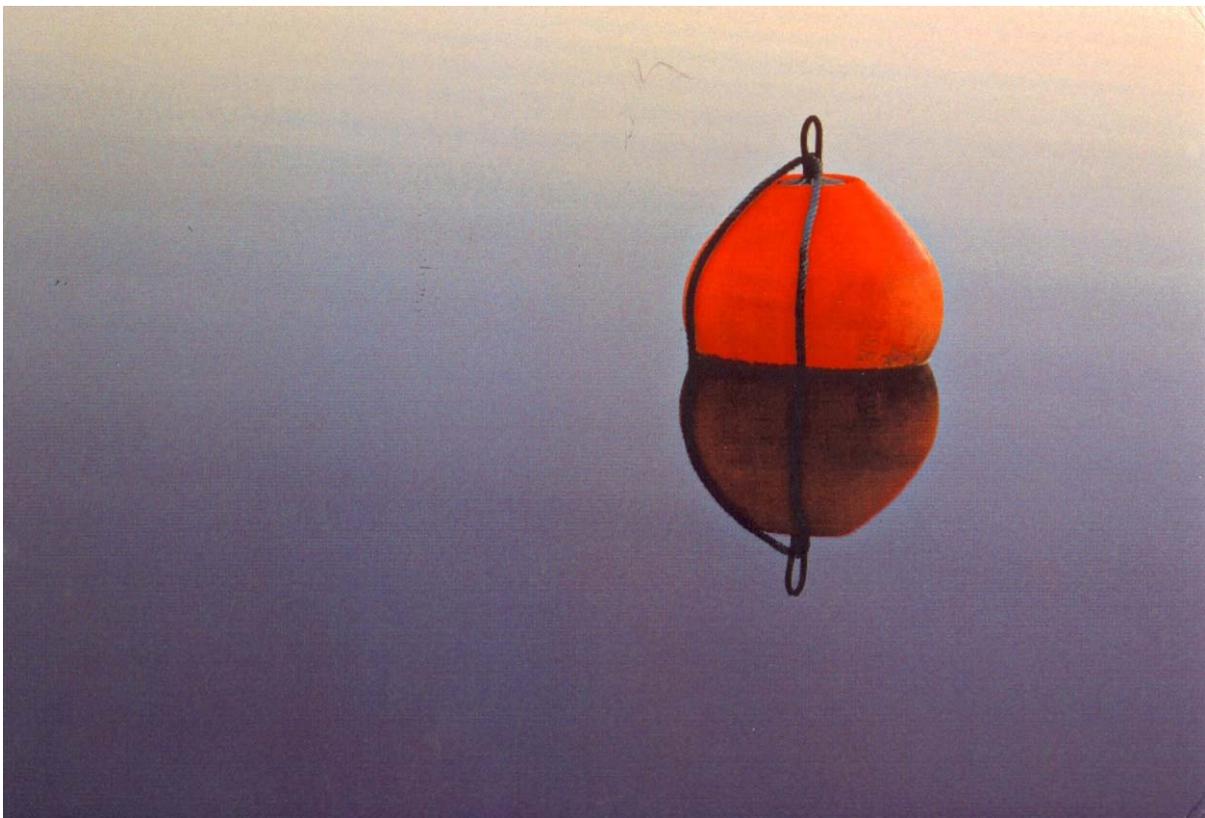NNDR-2009 in Nyborg 2.-4. April 2009

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Tobba Sudmann

(En)gendering body politics

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Summary
The aim of this study is to gain knowledge about what patients do to negotiate possibilities and constraints for recuperative encounters with physiotherapists. The historical tenets of Norwegian physiotherapy are recapitulated and contemporary gendered specialisation and work division are presented. The theoretical underpinning of the study, critical hermeneutics and the sociology of everyday life, are tied together by coining play as pivotal for understanding and interaction, and by embedding small behaviours as part of language. Hermeneutic understanding depends on the interpreters' background, comprised of symbolic, structural and subjective aspects. A focus group method is applied, construed as situated social gatherings: 4 groups of men, 4 groups of women, 26 women, 22 men, aged 18-77, comprising experiences with sports related injuries, chronic pain, heart or lung diseases, physical disabilities or medical unexplained disorders. Knowledge proposals: According to the participants, bodily changes and well-being depends on verbal, bodily and hands-on dialogues, and an attentive present therapist. The dialogical situation is precariously constructed; self presentation is planned to details and carefully enacted. Social institutions as gender imprint interaction, understanding and treatment. Pain is construed as action, and is a paradigmatic exemplar of how verbal, bodily and hands-on communication, self presentation and gender intersect in physiotherapy. Independent of age, gender or bodily concerns the participants challenge and negotiate cultural, medical or personal boundaries to enhance well-being and/or to reach personal objectives e.g. increasing pain for a greater good. The participants' accounts are interpreted as intentional human agency, and reconstructed as body politics. Construing vulnerability as strength, the participants appreciate some of the benefits gained from living with bodily constraints and challenges. Their actions and enactments create new body idioms and new accounts of health/illness.
Physiotherapy represents a field of practices where contradictory and covert social expectations reside. When social expectations are not met, patients may experience embarrassment, and recuperative interaction may be at risk. Social disruption may be ignored, remedied or laughed at. Laughter may be interpreted as a sign of embarrassment due to fragile interaction. By studying embarrassment and laughter we can listen for social dissonance, and imply some conditions necessary for the interaction to come off. Some necessary conditions are implied above; the participants, as patients, try to avoid embarrassing situations by asserting a personal body politics and warranting amendments to the interaction order of therapeutic encounters.
Keywords: Body politics, gender, agency, critical hermeneutics,

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Unpacking the "Disability Certificate": A Study of Media Discourse and the Ideology of Ableism in Taiwan

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Disability is a constructed social category, and the boundaries of dis/abled have shifted over time. In Taiwan, the concept of "disability" has been an official designation since the legislation of the "Handicapped" Welfare Law in 1980. According to the law, a "disability certificate" should be issued as a form of legal identification for all disabled citizens. In the official discourse, the certificate of disability becomes the ID allowing people with disabilities to gain legal recognition and claim welfare benefits. However, in the cultural sphere, the meanings of disability remain uncontested.

This study takes media as a contested site where not only is the ideology of the nation-state exercised and reinforced but also the everyday perceiving of disability is (re)produced and negotiated. Relying on content analysis and textual analysis, this study examines the media reports on "disability certificate" published in one major Taiwanese newspaper from 1980 to 2007. First, this study uses content analysis to sketch out a picture of disabled images and discourses in different historical periods. Second, this study uses textual analysis to conceptualize the images and discourses of disability in specific social, cultural, and political contexts. Finally, through an analysis of media reports and discourses, our study moves further to unpack the ideology of ableism in the Taiwanese public sphere.

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Jewish responses to Intellectual Disability: An Ethnographic Study of a Jewish School for Children with Intellectual Disabilities in Antwerp

Researchers, specialized in disability studies, describe the evolution of the concepts like handicap, disability, impairment and challenges. However, regardless of the concept used, there is always some resulting social impact within a determined social group. Some of these social responses are: discrimination, racism, indifference, etc. Whatever the reaction, it always reflects something deeper, something which arises from the culture's traditions.

Building upon the idea of social responses produced by social conceptualizations, this research focuses on Jewish responses to disability from a religious perspective. The research aim is to describe, ethnographically, how modern Jewish society is impacted jointly by religious traditions that might seem fairly contradictory to disability. How does Jewish society resolve the different concepts of sin and sacrifice versus seeking and integrating new knowledge and technology.

One of the arguments in this paper is that the culture is very important in determining the social responses to different phenomena and, it is assumed that religion is the most important cultural aspect present in different social groups and the basis of the dominant social construction(s). One of the hypotheses in this research is that despite people are not actively practicing their religion; they remain attached to its essential beliefs. Thus, a main argument in this paper is that despite the Jewish people not being homogenous in religious observation, nonetheless, they categorize disability in the light of religion which remains central to their culture.

Jewish view of disability, whether as something wrong or something incidental, derives from their beliefs. Consequently, whether and how they perceive disability; as a sin requiring sacrifice or as an incidental challenge that can be addressed by scientific methods becomes an interesting dialectic leading to a synthesis a uniquely Jewish response, a process worthy of study and better understanding.

This paper has as its principal purpose the investigation of the Jewish parents' conceptualization of their own experiences as parents of children with intellectual problems. The fieldwork site selected is Antwerp because of some specific and practical reasons. In Antwerp, there is a large community of Jewish people and there exists a special school for disabled Jewish children who are enrolled from different places around the world. In spite of recent statistical studies indicating that the majority of the Jewish population in Belgium is located in Brussels, it is in Antwerp where they are more identifiable, because that population is mostly Hassidic and more traditional and easily recognizable.

In relation to the objectives of this research, the majority of the theoretical assumptions and hypotheses have been based within the theoretical constructivist framework, which indicates that the words and concepts, allow to explain and to interpret reality. Concepts make it possible to organize the complexity of reality and make it more intelligible. Likewise, disability will be studied as a conceptualization or categorization.

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THE INVALID WELFARE ACT AND VOCATIONAL EDUCATION IN FINLAND 1947-1983

The Invalid Welfare Act (IWA) was enacted in Finland early 1947. The law defined an invalid as any person whose ability to work or otherwise perform was permanently reduced due to the loss or function of an organ to such an extend that it significantly hindered his/her everyday life or possibility to earn a livelihood. The law did not cover persons suffering from chronic illnesses, nor those for whom care could not beneficially be given because some physical or mental conditions were lacking. State resources for invalid welfare could be used to provide medical care, education and vocational training.

The IWA guaranteed state financing for the establishment and maintenance of vocational schools for persons with disabilities, so associations started to establish new schools with enthusiasm. Two-thirds of building and maintenance costs of the schools was financed by different sources of the state, but the share of financing of the associations was also significant. In 1960 there were five vocational schools for invalids, three for persons with lung diseases and one for blind and one for deaf in Finland. There were approximately 1400 students in these schools.

Soon after the enactment of the law, a lively discussion arose concerning the shortcomings noted in it. The most clear was its exclusion of chronic illnesses, such as rheumatism and tuberculosis. The act was supplemented in several stages in the 1950´s and 1960´s by including new disabled groups and forms of care. The vocational education based on the IWA reached its peak in the 1960`s, but after that the network of vocational schools started to reduce as small units were closed down due to expenses. The number of students also decreased because persons with minor disability sought their way to general vocational schools. At the same time the Social Insurance Institute of Finland and the insurance companies became more important providers of vocational training for the disabled. The provisions of the IWA were in effect until the 1980´s.

Research questions

1) Prior to the enactment of the IWA there was an Invalid Welfare Committee and during its work there was a discussion concerning those objectives of vocational training for the disabled which could be and were set. This discussion brings out various viewpoints on the educability of the disabled, the purpose of the training and its ethical and economic bases.

2) The records of the Invalid Welfare Committee clearly indicate the attitudes of various interest groups about the possible forms the training could take and the foreign models the committee had at is disposal.

3) By examining the educational decisions made on the basis on IWA and the school success of the invalid pupils we can determine how the act fulfilled the tasks set for it and the deficiencies that were noted in its practical operation. The archives indicate who was trained, what occupations they were trained for and how they succeeded in their studies, and who were excluded from training.

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PROMISING FACTORS PROMOTING INCLUSION OF PUPILS WITH MENTAL RETARDATION IN LOCAL SCHOOLS

This article tries to answer the research question 'what is the promising factors promoting inclusion of pupils with mental retardation in local schools'. The problem is enlightened by means of a literature review of publications on the theme in the three Scandinavian countries. Promising factors are supportive general frame factors (leaders' values and willingness to arrange for practical and financial resources), well qualified teachers, use of project method and pupils' skills of interaction. Although research in this field is scarce the findings appear to be valid and reliable due to a relatively high level of unanimity over country borders and because of the 'quality' of the researchers – the most influential are professors. However, one should be open for the fact that there are variables accounting for other tracks to accomplish inclusion in the society for these target pupils than by means of local schools. That is why this review also detects certain 'anti-inclusive' signs – or pinpoints other placements than the local school as the best solution for some pupils.

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Human Rights-Based Approach to Disability in Uganda

Human rights-based approach has increasingly been promoted especially with the UN Convention entering into force in May 2008. In theory, the approach has several positive significances to disability in development (Katsui & Kumpuvuori, 2008). This paper focuses on how the approach is operationalised in practice with the case study of Uganda. Thus, the paper tries to elaborate how such a normative approach is implemented into Southern countries in practice. This is part of a bigger research project entitled, "Human Rights-Based Approach to Disability in Development: Interplay of Disability-Sensitive Development Cooperation and National Policy in Uganda, funded between 2007-2010.

Fieldwork was conducted between January-February 2008 in Uganda for interviewing stakeholders of development cooperation projects on disability. Both decision makers such as the Minister and deaf women on the grassroots were interviewed for scrutinising operational values of this approach in their practices. All together 66 interviews were conducted, of which 14 were deaf, and 11 events were observed. Participatory research approach (Katsui & Koistinen, forthcoming) has been applied to try to make the research process and findings relevant to the Ugandan disability movement.

The preliminary conclusion is that organisations of persons with disabilities (DPOs) operationalise this approach differently to different actors. For instance, between Northern and Ugandan DPOs, the ideology of the human rights-based approach is the motivation as well as their strategic tool for implementing their project activities. On the other hand, Ugandan DPOs maintain this motivation based on the human rights principles but actually implement activities more in a charity-based approach to their members on the grassroots such as deaf women. Human rights terminology and concepts are unfamiliar to many persons with disabilities on the grassroots, particularly so for deaf women who were interviewed. The empirical findings imply that human rights-based approach requires certain conditions to be able to fully operationalise in practice. The paper concludes how the approach is materialised in Ugandan practice and makes implications of operational values of this approach from a critical viewpoint.

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Breaking Through the 'Chrome Ceiling'

Interest in leaders and leadership has never been so pronounced: Today, a myriad of consultancies offer advice and 'leadership development programmes' to organisations determined to gain a competitive advantage over business rivals. Burgoyne (2004) has estimated that around $36 to $60 billion US dollars are spent every year by organizations across the globe on such programmes. 'Leadership' has become big business. The modern business mantra appears to be that successful companies 'do leadership'; whilst those that don't, are making a big mistake.

Despite the prevailing interest in 'leaders' and 'leadership', the experiences and perceptions of disabled business leaders remains under-researched. Within leadership studies, the subject of disability is conspicuous by its absence, whilst within disability studies, existing research has tended only to confirm that disabled people are far more likely to be unemployed than non-disabled people; and when they are employed, they are likely to be working in lower paid and less valued occupations. Although some recent research has examined the ambitions of young disabled people and their attempts to move into the world of work, there is still an absence of interest in the experiences of those who are more established in their business careers.

This presentation draws on my own experience as a disabled business leader, and summarises the progress I have made in my PhD research project, which is an examination of the experiences and perceptions of disabled business leaders. The research reviews the emerging concept of 'followership' from within leadership studies, (Meindl, 1995; Hogg, 2001), and posits that it is the attitudes of 'the led' that play a critical role in determining the success, or otherwise, of a disabled leader.

In short, whilst nascent discussions on creating disabled business leaders appear to focus on what the disabled individual needs to do (a medical/individual model approach); my research will aim to show that a social model approach is more relevant and appropriate if disabled people are to break through, what has been referred to by Medgyesi (1996) as, 'the chrome ceiling'.

Key Words: Disabled Leaders; Leadership; Followership; Attitudes

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Disabled Children and Child Protection

Objective/purpose: This paper will present emerging findings from a study, funded by the Sir Halley Stewart Trust, which aims to scope current knowledge about child protection and disabled children, review social policy and practice in the field and pilot ways of seeking disabled children's views about child protection services. The research is due to complete in May 2009. The paper will focus on 'headline' findings from the literature review and interviews with 'key informants.'

Method: The literature review is being guided by a five-part framework for scoping studies (Arksey and O'Malley 2005). This involves developing the research questions, identifying relevant studies, study selection, charting the data and lastly, collating, summarising and reporting the results. The interviews with key informants will explore how effectively child protection policies around the UK are addressing the needs of disabled children. The interviews will be conducted face to face, using a semi-structured interview schedule, with representatives from government, social work, police, health, education and disability and children's organisations.

Emerging results: The largest study conducted about disabled children and child protection to date found that disabled children are 3.4 times more likely to be abused than their non-disabled peers (Sullivan and Knutson 2000) but this maltreatment is typically under-reported (Morris 1999, Kvam 2000, Lightfoot and LaLiberte, 2006). Although more vulnerable to abuse than non-disabled children, there is evidence that young disabled people are less well protected. A good deal is known about the characteristics and vulnerabilities of abused disabled children in terms of age, gender and type of impairment. Much less information is available about how they fare within the child protection system, although one British study (Cooke and Standen 2002) found that cases involving disabled children were less likely than others to be placed on the child protection register or receive protection plans. Very few studies have asked disabled children about their experiences of abuse or their views about the child protection system.

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Diane Mulligan, Sightsavers International

How disability practice informs policy: Uganda and Ghana

Sightsavers International is a non-governmental organization with social inclusion objectives that address the lives of blind people in developing countries. Research in our organization is gaining more prominence.

The aim of this presentation is to show how our grassroots research influences policy on disability issues, and how policy change informs our research. I illustrate this ongoing bidirectional approach with 2 case studies. These case studies will focus on community based rehabilitation. Sightsavers has gathered information, qualitative stories and statistical data from across its programmes in 2 countries to support the development of the forthcoming WHO/ILO/UNESCO guidelines on Community Based Rehabilitation.

I conclude that disabled peoples organizations in developing countries can play a role in shaping public policy. These organizations can use their own experiences to inform and develop domestic policy in country in order to secure the rights of disabled people.

Key words: Disabled people's organizations, policy, research, community based rehabilitation.

This will be an oral presentation in the 'grassroots' section of the symposium.

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Specialised disability services under change

The local government reform in 2007 has introduced new management principles in the production of specialised social services in the disability sector in Denmark. The local government reform reduced the number of municipalities and changed the division of labour between the state, regions and municipalities. In the disability sector the municipalities became responsible for financing all disability services, and most of the specialised services and advisory centres are now managed by the municipalities. In this paper I present the temporary results from a study of the local government reform and its effect for citizens with disability who need specialised assistance and advice. The study covers the period 2006-2010 and follows users, employees and managers in the specialised programmes. The focus is on how users experience the reform and how it affects their everyday lives, and how the reform influences the working condition of the staff and the managers of the specialised services. The paper is based on interviews with users, members of the staff and the managers from 20 specialised services covering different services like sheltered housing, sheltered workshop, special education and centres for rehabilitation and advising.

Key Words: Local government reform, specialised disability services, new public management, users with specialised needs.

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Adjustment in IDF Disabled Women: Equally Different

Keywords: Adjustment; Disability; Gender; Military.

As a single democracy in the Middle East, Israel has often resorted to employing its military forces in self-defense. Since its establishment, Israel sees itself as a "country in uniform", in which active participation in military and combat efforts is neither restricted to the male gender, nor voluntary. Unlike most women elsewhere, Israeli women have always had an active public image and a defined role in the military, even before the Israeli Defense Force (IDF) was established. Consequently, women are unfortunately subjected to military injuries and wounds which, in essence, are not unlike similar injuries among men.

The IDF acknowledges a person as disabled if he/she was hurt during military service, or other types of active duty in other security organizations which serve the country. While much scientific attention has been given to the implications of male military injuries, research regarding Israeli women who have been injured during military service is seriously lacking. The population of females who became disabled during military service in Israel is about 5% of all disabled veterans. Despite the fact that they were recruited by law and wounded/injured during active duty, female disabled veterans have not received ample scientific interest for many years. A single research examined the social attitudes towards this population, and found that gender was not a significant factor. Research in this field has found that American women who suffer from a military disability have reported alcohol abuse, post-traumatic stress, cognitive deficits, and suicide attempts.

Objective: The current research examines whether adjustment to disability among female veterans is similar to that of other groups of disabled persons, and aims at mapping and assessing a wide variety of factors which contribute to the process of adjustment to disability among this population.

Method: 346 disabled men and women from four groups (IDF disabled men; IDF disabled women; men whose disability occurred under civilian circumstances; women whose disability occurred by civilian circumstances), all suffering only from physical disabilities, were included in the study. All disabilities were not congenital, and occurred after the age of 18. Adjustment was measured by three parameters: physical health, mental health, and social functioning, and was examined by self-report scales, which provide a quantative grade while allowing the individuals to give a proper account of their own experiences.

Results and Conclusion: Results showed that in comparison with IDF disabled men, IDF disabled women receive less formal social support, feel more stigmatized and discriminated, have lower self-esteem, and suffer from increased emotional problems. Interestingly, it was found that while their salaries are significantly lower, IDF disabled women function better at home and at work than their male counterparts. In conclusion, even though Israeli society sees its injured veterans as "heroes", issues of women who were injured during their service go largely unnoticed, and their unique needs are not sufficiently addressed.

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Social networks – involving families and professionals surrounding children and youth with complex communication needs

Introduction
Children with severe communication disabilities are a vulnerable group in the community and are depending on the knowledge, skills and empathy of the people in their immediate surrounding, which include parents, sisters and brothers, relatives and professionals, i.e. the social networks (Blackstone & Hunt Berg, 2002; Anderson, 2006). The family is of great importance in supporting the communication and language development of the child. The professionals have to create conditions conducive to a positive learning environment, which demands knowledge of disability, language, communication and proximal zone of development (Lahey, 1978; Vygotsky, 1986; Bodorova & Leong, 1996). It is significant to consider persons with complex disabilities as active and participating parties in the developmental process (Light & Binger, 1998).

Children with disabilities encounter different hindrance in their daily life, in their communication with others and in their learning. Hindrance can be found by the individual himself as well by the persons in the surrounding and in the situation as in structures and principles of the society (Beukleman & Miranda, 1998; WHO, 2001; Anderson, 2002; Eriksson, 2006). Another reason can be found in indistinctive goals, effort and responsibility according to communication and language development of the child. Various kind of hindrance can be eliminated, among others by identifying and analyzing them, contextualizing them, illuminating facilitating phenomenon and increasing the awareness of the importance of communication by as well professionals as families.

The starting point of the current project is the social networks surrounding children and youth with complex communication needs caused of, among other things hearing and intellectual disabilities. The target group is children and youth of 8 to 26 years of age and who communicate in linguistic level, but the communication form is not sufficient to understand or express feelings, thoughts, and aims within the family or in daily life situations.

Aim of the study
The all-embracing aim of this project is to follow and illuminate participation and collaborative learning among participants in six social networks and communicative development related to children and youth with complex communication needs. Every network consists of 5-8 participants, i.e. family members, relatives, speech pathologists, special educators, teachers, pupil assistants etc. An underlying purpose is to developing assessment methods, analysing needs and support and to find suitable forms of cooperation.

Method
In focus are participation and activity of the members in every social network. The way of working is a process going on for about 2½ years with meetings four times a year and different tasks in the intermediate period. The tools used in this process are among others social networks interview, video – recordings analysis, reflecting dialogues and analyse of individual educational plans.

Part time outcome from the first year:
•Social Networks – six groups with unique prerequisites and needs
•Social Networks – result of the Inventory Booklet
•Individual Education Plan according to ICF´s conception.
•Video - recordings – what does the interpersonal analyses show?

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Madness in the mountains: lessons of mental health and resilience in exploring everyday life for people in recovery with 'psychosis'

This presentation presents emergent findings from an ongoing two-part study exploring the everyday life of people with long-term mental health problems living in isolated mountain and rural communities in North America and Norway. Participating informants were involved in the study design throughout the research process, and continue to be so. All have diagnoses within the broad category known as 'psychosis', primarily 'schizophrenia'. All informants have long-term histories of serious mental distress, including incarceration in psychiatric hospitals, treatment with psycho-tropic medication, and often including periods of involuntary commitment. At the time of involvement in this study, all informants had been out of hospital for at least two years and consider themselves to be in recovery, defined here as 'getting on with their lives', typically without help from paid, formalised services. This presentation will include a brief summary and critical gaze at what is called 'recovery research'. Much recent research literature describes recovery as a social process, involving social 'others' at family/local community and societal levels. The focus of this study explored the lives of people who are living far away from formalised services, and also often far away from most other people. In places such as rural United States experiencing serious economic decline, it is especially interesting and important to explore and understand how people with serious and often enduring mental health problems can manage their own daily lives, since many are without family or close friends, have no full-time employment, and have few (if any) social and health benefits.The methodological approach for this study is ethnographic in nature, with myself as primary researcher sharing everyday life-settings with participating informants and using an informal conversation style of interview. Seventeen participants from North America were involved during 2006 and 2007, followed up by six individuals in Norway in 2007 and 2008. Settings to meet were decided by participating informants, and mostly included visits in their own homes, work places, leisure-time activities, and being together at local community events and places. Each participant was met at least twice, and my 'interview'/ observation/ participation notes were reviewed by informants to be approved, altered or augmented. Findings thus far reveal that personal resilience and creativity are important, as well as often having close contact and social roles connected to nature and seasonal routines. Control over one's own life appears to be key, including where and when to have contact with others, thus linking the social dimension of 'recovery' with the important aspect of augmented autonomy.

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Hidden pain? What people with learning disabilities say about why they self-injure

Research considering the views of people without learning disabilities suggests that for them self injury has a clear function and is largely used as a coping strategy for dealing with emotional distress. They advocate the use of counselling or therapies to develop a broad repertoire of coping skills. Yet traditionally, self-injury in people with learning disabilities has been understood within a biological framework, or regarded as 'challenging' behaviour. It has often been managed by behavioural responses including aversive techniques, and medication. This paper reports on the first UK-wide research study that has worked with people with learning disabilities to understand what they understand as being the underlying reasons for their self-injury.

In-depth interviews were held with 25 people with learning disabilities over the age of 14 living in England, Wales, Northern Ireland and Scotland. Each research participant was visited an average of five times, and interviews took place verbally, using pictures, symbols, Makaton signing and interpreters. Two people with learning disabilities and personal experience of self-injury acted as consultants throughout the project.

Findings suggest that most of the research participants with learning disabilities had a considerable amount of insight about their self-injury. At root for many of them were experiences of considerable emotional distress which had been inadequately addressed. Many reported more than one way of injuring themselves that varied according to circumstance, opportunity and/or the depth of their emotional feelings; additionally, most regarded themselves negatively for self-injuring. Many of the research participants were able to indicate what they thought helped them most when they had self-injured. Very often, this was at odds with what they experienced in day-to-day life.

Our conclusions suggest that people with learning disabilities who self-injure need to have far greater attention paid to their own views about their self-injury and what meaning and function it serves for them. In addition, addressing the emotional well-being of individuals who self-injure is crucial, and access to targeted emotional support and psychological therapies could be beneficial.

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Researching and monitoring disability policies in the European context.

This paper reports on research activities carried out in 30 European countries under the auspices of the European Commission's 'Academic Network of European Disability experts' (ANED). ANED was established in 2007-8 to provide scientific support for policy evaluation and development by the Commission's Disability Unit. During the first year of activity reviews were undertaken of European law and disability statistics, plus thematic analysis of disability mainstreaming in EU Member State policy plans on employment and social inclusion. More than 60 reports were prepared in this process. The paper summarises the activities and key findings from this work and presents a state-of-the-art evaluation of key issues and concerns in policy development. The focus of the paper will be to draw lessons from existing knowledge and to raise questions about the challenges of monitoring and comparing national policy developments in international context (e.g. in relation to implementation of the European Disability Action Plan and the United Nations Convention). In particular, the paper raises questions about the role of national and international research in relation to policy monitoring and evaluation in comparative perspective.

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Enabling or disabling practice?: (Removing) psycho-emotional disablism within professional relationships with disabled people

For many disabled people, the effects of impairment mean that health and welfare professionals are involved in their lives on a regular basis. Existing literature drawing on the experiences of disabled people has illustrated the extent to which these professional-disabled people relationships, with their inherently unequal power balance, can be characterised by behaviour which is dismissive, patronising and prejudiced. This paper will discuss examples of psycho-emotional disablism - a form of social oppression which operates along emotional pathways – which were revealed through an analysis of the experiential accounts of people with physical impairments talking about their relationships with a range of professionals.

The inherent power imbalance between professional and disabled client means that psycho-emotional disablism is always potentially in the background. The prevalence of negative images and prejudice about disability within society can influence professional practice; for example a pregnant disabled woman may be offered a termination rather than support because of the assumptions that disabled people are dependent and therefore not able to care for others. I draw on my research data to provide other examples of professional practice which reveal psycho-emotional disablism in operation and show the emotional and practical implications this had for the disabled person. I illustrate the way in which this source of psycho-emotional disablism can also continue to exert an influence on someone's emotional well-being long after the professional relationship has ended. Examples are also provided of acts of resistance within these relationships which restored a degree of control and power to the disabled person.

I show how important it is that professionals are aware of someone's 'disability history' in order to realise how the long-lasting effects of psycho-emotional disablism can disrupt subsequent relationships with professionals, even when no active disablism is present. Thus a well-meaning professional may interpret the reaction of a disabled person as pathological when in fact it is the result of past experiences of being patronised or devalued.

However there were also examples in my research of good professional practice and I discuss how relatively small actions can have a huge positive impact on the emotional well-being of the disabled person being supported.

Finally I show how better training of professionals to include an awareness of psycho-emotional disablism would mean that they themselves don't become unwitting oppressors in the relationships with their clients. It is vital that professionals in the health and welfare fields are aware of psycho-emotional disablism and how it can impact on self-esteem and self-worth, if they are to work effectively with disabled people. In addition I reveal how it is possible to reduce/remove this aspect of disablism through attitudinal/behavioural changes which don't need to cost money, an important consideration in the light of the current crisis in the UK in funding of health and social care services.

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Existential Angst & Autism Spectrum Disorders: understanding relationships where one partner has an autism spectrum disorder (ASD)

Objective/Purpose

To understand the demands of sustaining long-term relationships on couples where one partner is diagnosed with ASD.

Method

A qualitative study based on a sample of unstructured interviews with heterosexual couples where one partner has a diagnosis placing him or her on the autism spectrum. The couples interviewed discussed the significance of having a confirmed diagnosis of autism, and how living with autism or living with a partner with ASD affects their lives. The analysis of the interview data, based upon grounded theory, presents a model of relationships where one partner is autistic.

Results and Conclusion

Receiving a diagnosis of ASD invites those receiving it to revaluate and revise their autobiography; they now know (perversely) that 'nothing is wrong' with them, and embark on a process of trying to differentiate their character from their medical condition. For partners, the diagnosis provides an opportunity to reassess perceived moral failures within a medical framework and they, too, try to distinguish between self and symptom. In this new environment, some partners diagnosed with ASD attempt to change how they conduct themselves using newly acquired insights into their behaviour and actions. Their partners are faced with the prospect of embracing and supporting or rebuffing the possibility of personal change, and thus changes to their relationship.

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Negotiating daily strategies and routines

Objective. This qualitative interview study investigated the ways in which Icelandic parents of children with physical impairments negotiate their everyday strategies and routines. The parents' relationships and communications with the health, educational, and social services were also explored.

Method. A total of 17 parents (14 mothers and three fathers) of children aged 7-13 were interviewed. Data analysis was primarily based on grounded theory procedures, emphasizing the constant comparative approach.

Results. The daily enactment of routines of the 14 families was quite diverse. Many parents described efficient ways in accommodating to and balancing their everyday events. Nevertheless, for some children, especially those with the most significant impairments, a large part of the family's day revolved around caring and advocating for their child. As a result their daily schedules were often extremely tight. Some parents described roles that demanded an unreasonable or burdensome amount of their time and energy. Family resources such as their adaptability, commitment, social support and ability to cooperate with the service systems appeared to be decisive factors in how they succeeded in negotiating their routines and communicating with the different professionals involved. Most parents became increasingly critical of the services provided as their child grew older. In general, the parents wished for mutual respect, joint decision making in planning services, and collaboration with the service providers. The aspiration for active but manageable roles that did not demand a burdensome amount of the parents' time and energy was evinced.

Conclusion. Each family values, resources, social support, and space were important factors in their development and choice of daily routines and strategies. The results indicate that service providers must carefully attend to each family's lifestyle, culture and wishes.

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People with disabilities and political participation

An important part of the term citizenship refers to the individual's opportunity to participate actively in the political life. The paper raises the question as to what degree persons with disabilities get the opportunity to take part in political life at municipal level. It looks at what is done to adapt the physical environment to persons with disabilities, how the meetings are organised, if the representatives get information and documents in the necessary format and to what degree representatives in need of assistance during the meetings get it. The paper further looks at what role disabled politicians take. Do they differ from non-disabled politicians? Will they mainly act as advocates for disabled people, be sector politicians or do they display a general approach to their political work? The paper is based on a survey sent to representatives of the municipal councils in four Norwegian counties and to the secretaries of the executive committee in the same municipalities.

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Different perspectives - different possibilities

This paper is based on a PhD-project which focuses on the school situation of pupils with intellectual disabilities in secondary school. The purpose of this paper is to explore what kind of child perspective one can identify in the employees practise, and how divergent perspectives create different possibilities in pupils' everyday life. In this context the concept employees includes both teachers, assistants and special teachers. The data are based on weeks of fieldwork where both interview (N=56) and participant observations are included. There are interviewed ten pupils with intellectual disabilities at seven secondary schools in different regions of Norway, as well as their parents or guardians, employees at the pupils' schools and at the educational-psychological support services. The pupils attend special education schools, department of special education at mainstream schools and mainstream schools. The interviews and field notes are analysed from a hermeneutic perspective.

The findings show that one can identify quite different perspectives on pupils with intellectual disabilities in the employees practice. Some employees mainly emphasise these pupils well being at the present. A common feature of several of these employees is that they let the pupils themselves participate quite a lot when it comes to decision-making during school hours. For instance the pupils have influence both on what their curriculum shall be, how to work with different subjects, and whether they shall stay in class or work on their own outside class. Others employees pay more attention to the pupils future. Their pupils have got some, but not comprehensive, influence at the content, methods and location during school hours. Even though these employees focus on the pupils' future, it varies what kind of knowledge and skills they find useful for the pupils life after leaving school. Summarised one from a child perspective might say that some employees perceive the pupils mainly as human beings (with limited potential), while others focus more at the pupils as human becomings (where it is important to make good use of the pupils potential). This difference in perspective is quite interesting since all pupils by Norwegian law have the right to develop their abilities and qualifications (§1-2), at the same time as they have got the right to attend school environments that promote their well-being (§9a-1).

Key words: School, child perspective, intellectual disability

Request: I know there is might going to be a special session concerning methods in research with people with intellectual disabilities at the conference. If so and if it is possible, I do wish to attend this session and therefore wish to not present my own paper at a parallel-session going at the same time as the method-session concerning intellectual disabilities.

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Communication board: possibilities and constraints.

Communication boards have been developed to make it possible for communicatively disabled people to communicate with their surroundings. Communication boards are thus thought of as a resource of communication. This paper however shows how the dynamics of social interaction can counteract this intention and reduce the communicative potential of the board. For communicatively disabled people social interaction is a two-edged sword: on the one-hand the collaboration of communicative partners makes the communicatively disable part's actions "expressive" but on the other hand the well-intended collaboration by the non-disabled part may also delimit the range of contributions that the communicatively disabled part may make to the interaction. This point will be demonstrated through a micro-social analysis of an excerpt of social interaction between a young boy with cerebral palsy who uses a simple communication board and his pedagogue. Thus besides demonstrating the paradoxical effects of social collaboration in communication with communicatively disable persons, the paper aims at demonstrating how the method and results of micro-social analysis can contribute valuable insights to the planning and evaluation of AAC intervention.

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What kind of research does Nordic researcher publish – and is our research user-friendly?

It is an ongoing discussion in the disability research communities if disability research contributes to new knowledge additionally to ordinary social and humanistic sciences. It is also an ongoing discussion and almost a claim from different interest groups of disabled people to become involved in research and/or if disabled researchers in the research area contributes with other knowledge than non-disabled researchers do. These discussions correspond to some degree with political discussions and legislation of antidiscrimination and usability. In this field there is a mixture of concepts like user-friendly, user involvement, user relevance, user direction and usability. These concepts can be understood as concepts within two contradictory ideological and theoretical paradigm; respectively radical critical theory and new liberalism. This presentation is based on a review of publications done by Nordic researchers in the last five volumes of Scandinavian Journal of Disability Research (SJDR) and Disability & Society (D & S) during 2005 – 2008. Totally 38 articles are involved from SJDR, and 13 from D & S from all the five Nordic countries. The articles have been reviewed according to topic, research methods and what kind of knowledge they produce. The discussion tries to elaborate challenges and possibilities in the relationship between research as a professional phenomenon in interaction with its historical and social context. There seem to be mixed signals in the existing research whether Nordic research are moving towards a stand-point-epistemology of disability or not.

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Beyond Binary Barriers: Chronic Illness as a Hybrid Experience and the Need to Reconceptualize the Health/Illness Binary

This paper aims to contribute to the conceptualization of the question of chronic illness as a category of impairment and to the creation of what I have been calling an interdisciplinary epistemology of chronic illness. I will start by advocating, in line with Susan Wendell and Carol Thomas, the absolute need to include chronically ill people in the disabled people's movement and to conceptualize chronic illness from a social oppression angle rather than a social deviance lens. Based on the fieldwork I have been doing with chronically ill people and in an interdisciplinary range of sources, I will then try to contribute to a much needed reconceptualization of the question of chronic illness focusing on two main moments: first I will draw from the notion of hybridism to look more closely at the experience of chronic illness and lastly I will focus on possible reconfigurations of the health and illness binary.

As my research seems to indicate, chronic illness often exists in a borderland space that clearly defies binaries. Chronically ill people cannot accurately be classified as either sick or healthy and often their experience is extremely fluctuating and defying of simplistic categorization. It is therefore important to question biomedicine's rigid premises regarding health and illness and contribute to a much needed interdisciplinary space that will rescue these concepts from the exclusivity of the biomedical model and invite new ways of looking into this matter. To contribute to this discussion, I draw from Bhabha's and Anzaldúa's emancipatory concepts of hybridism to try to discuss the often mixed and fluctuating experience of chronically ill people. This space "in-between", used by the aforementioned authors to refer specifically to the colonizer/colonized binary and miscegenation, can, I argue, also be useful to think about how we perceive the health/illness binary, the hierarchy between the two, and the difficulty in imagining a latitude where both touch and interact. This concept is also helpful in trying to conceptualize this space of frontier that chronically ill people often inhabit.

I will then proceed to question the health/illness binary discussing it more in detail and proposing the need for a model that bears into account the interconnectedness and interdependence between these two spaces. Some authors such as I. K. Zola have called our attention to the fact that the biomedical model's construction of illness as relatively infrequent, unusual, or an abnormal phenomenon is in fact far from real. However the biomedical model has become so prevalent that we seem unable to think outside its box. To try to propose a tentatively non-binary model to look at health and illness, I will seek to draw from Lacan's formulation of the mobiűs strip later reconceptualized by Elizabeth Grosz in order to present a non-dualistic model of the relationship between mind and body. I will therefore argue that the mobiűs strip model, with its inflection of one side into the other, could be a good starting point for a much needed reconceptualization of the health/illness binary.

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Evaluation of AKKTIV parental education

The aim of this ongoing project is to evaluate AKKTIV parental education. AKKTIV stands for Augmentative and Alternative Communication (AAC) Early Intervention and consists of two parental courses provided to parents who have children with communication disabilities aged 0-six years. Through increased knowledge and through the opportunity to share experiences, the purpose is to improve the family's communication situation. The parental education is given in to steps. The first course, "ComAlong", consists of eight occasions aimed at providing the parents with knowledge of communication, communication development and communication support and also the opportunity to use pictorial based AAC with their children. The parents who apply for the next step, "ComHome" learn more about how to use AAC in their homes. Experiences and video tapes are shared and discussed during the group sessions.

The aim of the research project is to study the effects of AKKTIV when it comes to the communication between parents and children, the development of the children and the parents' experiences of the interaction with their children and the impact on their parental role.

Methods: Data collection is ongoing and takes place pre, between and post the two courses. So far pre and between data has been collected from 20 parents and post data from 8 parents. These numbers will be considerably higher in April. The data consists of questionnaires, video-tapes of play situations in the homes collected before and after the courses and also focus-group interviews with parents and course leaders.

Results: The results so far look very promising. The children's communication development as measured with SECDI (Swedish Early Communicative Inventory) has increased significantly and there is a trend for less perceived negative impact of the child on the family and for parents to rate their interaction with their children more positively. During the presentation preliminary results will be presented alongside with some new data from a focus-group study.

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Communication using Speech-Generating Devices at Home

The main purpose of this study was to investigate whether and how the introduction of a speech-generating device (SGD) in activities at the homes of children with autism spectrum disorders (ASD) influenced communication. Four children aged between five and seven, at different stages of communicative development, participated in the study. A family-centred collaborative problem-solving model was used as a basis for the intervention and the decision-making process during selection of activities and design of the SGD applications. The children and their parents were videotaped before and during SGD intervention. The videotapes were coded along five dimensions: role in turn-taking, mode, function, effectiveness and engagement in activity. The activity based communication analysis (ACA) method was applied to compare communication before and during intervention in the included activities. Pre- and post-interventional interviews with the Vineland Adaptive Behavior Scales (VABS) were done for all children.

The results showed an increased level of communicative effectiveness during SGD use for all children and in all activities, regardless of communicative level at the start of the project. Pre- and post-interventional interviews with the VABS showed enhanced development on the supplementary norms for children with autism. Regarding the three home activities examined (mealtime, story reading and 'sharing experiences of the preschool day'), those where the goals were mainly communicative rather than practical resulted in a more marked increase in communicative effectiveness during SGD use. The mealtime activity, in which almost all research so far into the effects of SGD use in children with autism had been done, may not always be optimal in home interventions. The fact that the parents were instructed to use the SGDs when communicating with their children brought about positive changes: the partners came closer to each other, the sub-activities and goals were better synchronized and the pictures and vocabulary on the SGDs offered a shared concrete frame of reference. The comparison of SGD use in different activities in home and school environments indicated that characteristics of the activities seemed to predict outcome with respect to SGD use. During the morning circle activity at school and story reading at home, the directive role of the adult resulted in more similar patterns than the other two home-based activities. This points to the following clinical implications regarding SGD intervention at home: SGDs can be used to increase interaction and communication between children with ASD at different communicative levels and their parents, but there also seems to be a need to give the parents more basic instructions regarding interaction and communication strategies.

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Studying pedagogies and didactics towards pupils and having an anthropological approach

The aim of the study, presented in this abstract, is to examine how professionals construct pedagogical and didactic surroundings for children diagnosed with Autism Spectrum Disorder

The scientific approach and the design in the study is social anthropological. It draws on Pierre Bourdieus epistemology and Frederik Barths methodology. It implies a fieldwork in four different school settings: A special school, a special class, a folk school, and a free school (progressive and liberal).

 The field of Special Pedagogies and of Autism is constructed and data is produced:
•	Interviews of teachers on their assumptions, theoretical beliefs and educational background.
•	Field observations of situations in practice where professional define and construct actions towards children. These written down as narratives.
•	Focus interviews of teachers where they comment and discuss five narratives from the field study.

The aim of the study is to examine the process when professionals construct pedagogical and didactic space for pupils, and it's an ambition - in constructing the object of study (and the design that follows) - not to be lead by common-sence assumptions and normative doxa in the Disability research field on pupils and schools, pedagogies and didactics. It's a methodological ambition to break with these assumptions as an ongoing process in all dimensions and periods of the study. At the same time it's assumed to be impossible to approach and analyze data (and practice) without assumptions and instruments of knowledge (that entails assumptions). The researcher will have (normative) assumptions and must try to get free from them in order to break down connections between common-sence knowledge and the scientific examination. In order to enable a bottom-up approach to practice or to capture 'the construction' of practice (didactical and pedagogic surroundings) from the perspective of the teachers in contexts. The positions the 'disability-research field' is not the only point of departure in the analysis.

The finding of the study is that professionals draw on a multitude of theories, attitudes and practical strategies and that the pedagogical and didactic space they create is complex: It contains psycho-medical theories (attitudes and strategies) about diagnoses and pedagogical models, sociological theories (attitudes and strategies) about exclusion and inclusion and theories (attitudes and strategies) from a broader educational field on pedagogic and didactics.

Another finding is, that these different dimensions and the way they function together or could function together, ought to be an integrated part of the professionalism of the teacher (who teaches children that are diagnosed).

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Disability and 'Culture': Critical reflections on the intersection of anthropology and disability research.

Key words: disability research, anthropology, culture, knowledge, critical theory

In this paper I will explore some of the valuable contributions that anthropology has made and can potentially make to the study of disability, such as the cross-cultural approach, understandings of personhood, as well as the critical understandings of the concept of 'culture' itself, among others. By no means has the field of anthropology produced a coherent and generally agreed upon formulation of the culture concept, but the extensive debates within the history of the discipline on this issue also make it apparent that the concept of 'culture' within disability studies, generally speaking, is often not treated with a great deal of theoretical sophistication. However, I will also discuss some of the potential that disability studies has to enrich anthropological understandings of disability pertaining to, among others, certain assumptions underlying the cross-cultural approach, the problematic placement of the anthropology of disability under the branch of 'medical anthropology,' and the construction of 'otherness' that is central to the anthropological project. The multidisciplinary nature of disability research has great potential to mutually enrich a number of disciplines and approaches to researching issues concerned with disability. Yet this mosaic of scholars from diverse intellectual and personal backgrounds also has the potential for misunderstanding and talking past one another given a range of disciplinary assumptions and understandings of key terms, concepts and the nature of research.

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Universal design, ethics and diversity: On human life in the city

What is a good city and urban space for human beings in modern big cities? How do people with various impairments experience the urban space? This study focuses on the urban space as a place for all humans, included people who live with impairments such as loss of sight or reduced mobility. Many people experience these kinds of impairments through lifetime, which is one reason why it is interesting to explore the interaction human being-place from this perspective.

I understand impairments as a continuum through lifetime. The American philosopher Martha C. Nussbaum describes it like this: "human beings are vulnerable, temporal creatures, both capable and needy" (Nussbaum, Martha C. Frontiers of Justice, p.221) As embodied creatures we can not exist in a placeless world. The built architecture is therefore of both ethical and democratically importance and interest, since design has got the possibility both to enable and disable individuals.

National and also international politics states that all people should be included and able to participate in everyday social life. Accessibility is a prerequisite for participation and universal design is in Norway a chosen strategy for participation, equal opportunity and equal rights. How can we discuss and understand the concept of universal design, ability and disability, accessibility, "disaccessibility" and participation in urban spaces in big cities?

In order to learn more about how the urban places and space effects on the individual's activity and ability to participate in society I conducted an empirical study, where I have examined urban places in Oslo together with visually impaired people and people with reduced mobility, and also some people without such impairments. I interviewed them about their use of the cities' places, sidewalks and streets while we were walking through an urban space. The method being used, I call walking-dialogue together with on-site examination. This study is a part of my doctoral thesis: Ethics, diversity and universal design. On human life in the city. From the perspectives of phenonomenology and hermeneutics I try to understand the interaction between the human being and the built environment.

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It's your decision: negotiating consent for research

Key words: Research Ethics, Mental Capacity, Informed Consent

Objective/Purpose
A fundamental requirement of ethical research is the negotiation of informed consent with participants. However what makes consent 'informed' can be contested, particularly with people whose decision making capacity may be uncertain.
The 'Who decides?' project aims to explore how people with learning disabilities are supported to make everyday decisions, and how their 'mental capacity' to make decisions is assessed. This presentation will turn the lens on the researcher and discuss how consent to participate in the study was negotiated with a sample of people whose capacity may have been in doubt. It will also present examples of ways in which people were given information which supported them to decide whether to take part in the research for themselves.

Method
In England the Mental Capacity Act 2005 provides guidelines for researchers working with people who may lack capacity to consent to research. This project modelled the principles of the Act in negotiating consent for people with learning disabilities to participate. This was undertaken on a person centred basis in order to reflect the individualised communication needs of participants. A reference group comprising people with learning disabilities gave advice on the production of accessible materials for participants.

The study sample included people with learning disabilities and their support worker(s), with the research following three stages for each participant. In stage one three introductory 'getting to know you' meetings were used to develop accessible research materials that met the participant's individual communication needs and to assess their capacity to consent to take part in the study. Stage two involved the video-recording of participants and their supporters while they engaged in their everyday tasks, with a focus on decision making acts. In stage three participants reviewed videos and were invited to comment on the recordings. The focus of this presentation is drawn from field notes recording the experiences in stage one above.

Results and Conclusion
Drawing on emerging findings this paper will present practical examples of how consent may be properly negotiated and discuss some of the challenges to researchers in accomplishing this.

Participants here have responded better when information about the research is presented in an innovative way, using props and 'live' examples of observations. This approach made the implications of consenting to the project more understandable and I would argue therefore more 'informed'

I will discuss how support workers, in their role as gatekeepers, played an important part in negotiating consent but also reflect on how their position may have compromised accepted principles of 'ethical' research.

Overall I will argue that adopting a flexible research methodology could allow for those previously considered incapable an opportunity to share their views in social research.

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Impairment, Cure and Disability Identity

This paper is reflective in nature and is concerned with two key questions. The first relates to impairment and cure and the subsequent impact of cure on a person's identity. Due to the rapid advancements witnessed in medicine, this is likely to be a question of increasing importance. This is explored not only at a personal level, but within the wider context of the disability community. In deliberating these issues, I reflect upon my own personal experience: I was born with congenital cataracts and registered as a visually impaired person for 42 years. In 2004 I underwent eye surgery, which proved successful. However, I was left questioning whether I would now be perceived and classified as an 'outsider' by other disabled people. Would I still be valued by the disability community or would I be viewed as someone who had crossed over to the other side, the side of so called 'normality'?

The second part of the paper reflects upon and questions my changing role as a disabled researcher to a non-disabled researcher. I had started my doctoral study as a disabled student and I explore these experiences and my later position as a non-disabled researcher.   As a disabled person, the debates surrounding the purpose of research and the position of the researcher were important to me and these were reflected in my research design and methodology.   I was an 'insider': I was a disabled person researching the experiences of other disabled people.   A growing body of evidence had identified the concerns and unease expressed by disabled people regarding the potential misrepresentation of their experiences by non-disabled researchers. These fears were important to me and I hoped that those involved within my research would feel that I had an understanding of the experiences they discussed. However, would this relationship change and, importantly would this impact on my research data and findings?

The answers to these questions raise a number of important issues associated with the attitude of disability activists and academics towards the concept of cure. It has been argued elsewhere that many disabled activists would refuse treatment that promises a cure and this has implications for the disabled person who chooses the path of treatment and cure. The conclusions reached focus on concerns relating to belonging and 'insider'/'outsider' status and acceptance/rejection from within the disability community.

Keywords: Identity; cure; acceptance; insider; representation

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Chinese Adults with Learning Difficulties in Britain.

Individuals with learning difficulties who identify as culturally Chinese who are living in Britain are underrepresented within social groups, related academic studies and in the evaluation of services. There is no previous research done, that specifically seeks to explore the understandings and experiences of this group. Nor is there any published material that specifically explores public attitudes towards this group or their family and carers and their experiences. This study has not only contribute towards the knowledge of this underrepresented minority group, but promoted the voice of people with learning difficulties their family and carers in the development of services. The aim of the current study was to examine the attitudes of the Chinese community and how this may impact upon the access, design and delivery of health and welfare services for people with learning difficulties. The study sought to answer Specific questions that were raised by the Chinese Community Centre – Birmingham in their effort to provide specific user led services. A mixed methodology of questionnaires and focus groups was used. All participants were members or associated to the Chinese Community Centre Birmingham. The attitudes of participants towards people with learning difficulties were gathered by means of a study survey that was translated into Chinese. Further, the study investigated the service experiences of families, carers and people with learning difficulties through an interpreter/translator surrounding the access, design and delivery of services through two focus groups in order to gather rich in-depth material. One focus group was be made up of six participants that were family and carers of a person with a learning difficulty. The second focus group was be made up of three participants with a learning difficulty plus their carers/family. The focus gave each participant an opportunity to express their experiences in their own words through an interpreter/translator. The paper describes the process of the study with particular focus on the use of an interpreter/translator and explores the implications of its findings for people with learning difficulties who identify as from a Chinese community and service providers. Analysis of the study material will provide an insight into any issues surrounding the development of appropriate services. The study worked closely with an interpreter/translator in producing research findings and was presented in a report to the Chinese Community Centre Birmingham.

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Why disability studies needs philosophy?

While disability studies research has produced a highly useful reconceptualising of disability as a social phenomenon, and has produced useful empirical analyses, in general it lacks essential dimensions of theoretical scrutiny provided to do justice to the complexity of the phenomenon. Philosophers, on the other hand, have traditionally been sloppy in doing their homework regarding the empirical realities and facts about disability, and have tended to treat disability in a stereotypical manner. Yet, the conceptual and analytic rigour typical to philosophy seems to be exactly what the theoretical development of the disability research field needs. In this presentation, we offer an analysis that supports the previous conclusion, and also some rudimentary guidelines for fruitful philosophical endeavours in disability research.

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De-institutionalisation in Europe

Finnish Association on Intellectual and Developmental Disabilities (FAIDD) has gathered a research data in cooperation with EASPD. The data consists of literature on de-institutionalisation and it was collected by a questionnaire directed to all European countries. The main goal of the research "De-Institutionalisation in Europe" is to get an overview of the process in Europe, especially in non-english speaking countries, and to have more information on questions as how is different groups of institutional care affected, what are meanings attached to concept and what kind of interests and contradictions are related to the de-institutionalisation process. The method is a meta-analysis of literature material provided by the questionnaire. The report has been published in March 2008.

There is no widely accepted or general formulation on what is meant by De-institutionalisation concept. It varies a lot in different contexts and it has a content which can be seen as a contradictory in nature. As a societal and cultural process it has many meanings and uses, which are connected to individual life worlds and conditions, group processes and communities and are bound to different organisational settings. In addition De-institutionalisation is deeply rooted in institutional basis of the society. Although it has been a major effect for decades it has been not studied as a whole. There is a need for clarification of the concept and need of a research of the process.

On the basis of the analysis the research material have been divided into three "zones": Eastern, Central and Southern Europe. These "zones" represent different phases of the process in view of historical, societal, cultural, and economical factors. To start with Eastern European Countries, they represent a situation where old traditions and norms meet guidelines of shaping the economy according to principles of current developments of capitalism under the umbrella of European Union's integration. In Southern Europe cultural struggle for de-institutionalisation has a relatively long history. Moving away from big institutions and towards community has been a major challenge. This has meant struggle for the rights of the individual to live his or her life as an active member of community and society. The transformation has also meant changing the role of patients and the disabled in community and the meaning of illness and handicap. In Central de-institutionalisation has been going on for some twenty years. Normalisation, integration and living in community have been slogans of the process. New elements and developments have now been subjective rights and individuality. However, in spite of improvements in the quality of life, a lot remains to be done. The cultural process is still on its way in a substantial manner. Everyday life outside institutions is a challenging matter reaching the point where to combine autonomy and responsibility and fulfilment of individual needs.

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Dedomestication: Something for disabled people and their carers alike?

Objective/Purpose: Earlier basic concepts used in comparative welfare research do not fit well for the study of how care services serve the needs of disabled people. Mainstream concepts like decommodification refer to cash benefits, not to support and care. Also defamilialization refers primarily to economic independence – and in connection to family care it has a problematic connotation implying 'politics against the family'. The purpose of this paper is to look for a concept that would suit better for the comparative study of care policies for disabled people – and to discuss whether the same concept could be useful also when analysing support given to family carers.
Method: The paper is based on a review and discussion of popular texts from both comparative welfare studies and disability studies, trying to combine and develop their conceptual perspectives.
Results: A concept of 'dedomestication' is suggested as a new conceptual tool for comparative research of policies and services for disabled people and their carers. 'Dedomestication' is defined as the degree to which people can participate in society, including labour market as well as social activities, outside their families. It implies that people are not confined to the domestic sphere. It does not mean self-sufficient 'freedom from family' but an opportunity to have also a social life. This is an objective that can be shared by both disabled people and informal carers and that can be used as an approach in evaluating the outcomes of care service systems.
Conclusion: Comparative research on care policies and services is in need of new conceptual approaches that put emphasis on the needs and wishes of disabled people and family carers alike. 'Dedomestication' is suggested here as a perspective that does not separate these groups from one another or show their needs as opposed to each other but that instead provides a common framework for research and development of support systems.
Keywords: dedomestication, disabled people, carers, care services, comparative research

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Caring for a daughter with ID in managing menstruation: Mothers' perspectives

Objective/Purpose The concerns of lifelong mother-carers' experiences of providing help for her daughter with ID who has high support needs in managing menstrual care are rarely addressed. This qualitative study aims to focus on these mothers' perspectives and experiences, such as what their caring tasks include, what they think about this caring work, what are their experiences of management approaches, whether they receive any help from formal or their informal networks and what assistance they think should be available from formal systems, in managing their daughters' menstrual care.
Method   Twelve mothers aged 40-76 who have a daughter with ID (aged 18-43) who needs to be fully helped in menstrual care including obtaining, changing and disposing menstrual pads were interviewed at their homes from September to November 2008 in Taiwan.
Results None of the mothers perceived the menstrual care task of giving help for their daughters' menstrual care as difficult; no mother blamed this task or had thought about to have their daughters' uterus removed (hysterectomy). A couple of mothers even needed to clean their daughters' pants several times a day for dealing with their daughters' special care in menstruation (e.g., dislike to use pad), but they did not show any complaint. Some of mothers might have a family member such as a sister of their daughter with ID who could give assistance in this; but mothers would rather carry on this task by themselves. In order to provide a better care for their daughters in managing menstruation, the participants also had a unique way to carry on this care work including buying less cost, more comfortable and easier cleaning pads, diapers and pants for their daughters. Some participants mentioned they used the general family subsidy from the government to buy their daughters' pads or diapers. The financial cost of menstrual pads or diapers were a big issue for many interviewed families; however some mothers mentioned they could not get any specific financial support in this regard and they did not think the government will offer this help even in the future.
Conclusion The mothers' experiences of giving help in their daughters' menstrual care need to be concerned by the society and policy makers in order to provide more instrumental support to these mother carers.

Keywords: intellectual disability, menstruation, mother, caregiver, Taiwan

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Inclusion and the daily life of adults with intellectual disabilities

Background: 'Inclusion' is the target for people with intellectual disabilities in Norway. The demographic group that is least included in postmodern society, despite verbal ideology, is that of people with intellectual disabilities. This paper focuses on inclusion in leisure activities, housing and friendship. What are the realities?
 A radical social reform in 1991 (the 'responsibility reform') closed regional institutions for persons with intellectual disabilities and returned them to the municipalities to give them living conditions, services and private flats in the community like other people. The intention was inclusion in society and in the neighbourhood.

Purpose of study: Answers to the question about social inclusion are based on material from the project: 'Double ageing: Living conditions and the quality of life for persons with intellectual disabilities and their elderly parents'. The purpose of the project is to study living conditions and daily life as experienced and related by people with intellectual disabilities and their parents, based on their life histories.

Method: In-depth transcribed interviews with twenty elderly parents (62–86 years old) and five adult children with intellectual disabilities concentrate on their everyday life situation, quality of life and interrelated life courses. (The twenty sons and daughters are between 30 and 51 years of age.) The interviews are analysed from the perspective of life course theory, covering past, present and future prospects.
Results: There is a great gap between ideals and realities. The everyday life situation for intellectually disabled persons living in their own homes is often experienced as unpredictable, with great social discontinuity. Discontinuity in staff with a frequent turnover of personnel represents a persistent challenge for these people, influencing their quality of life and social life. The staff are often numerous, working in small part-time jobs, without formal qualifications. This system is likely to give the staff only limited knowledge of the inhabitants' individual needs. In rural areas the system is experienced as being more stable than it is in large cities.
    Parents report that their adult children lack friends and do not make contacts in their neighbourhood. Support contacts or leisure contacts – important links to activities with non-disabled people – are often lacking. The parents often have the task of recruiting such assistants. According to the parents, it is mainly their responsibility to include their adult children in informal social life.
Conclusion: The hardest part of social inclusion for adults with intellectual disabilities is in informal life. The paradoxical position and challenge for public services is to establish informal contacts by means of formal measures and arrangements. Apart from contact with their families, people with intellectual disabilities are segregated and together with either staff or others with intellectual disabilities nearly all the time. Inclusion is failing.

The paper discusses possibilities and limits for reducing the gap between ideology and reality with respect to inclusion.

Key words: inclusion, segregation, life-course, everyday life, intellectual disability

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Dis-junctures: An historical and anthropological study of disability, citizenship and sexuality in Denmark and Sweden, from 1925 to the present day

The project is inspired by ongoing discussions about citizenship and exclusion. We contend that research on sexuality and disability can contribute in important ways to debates about autonomy and inclusion in society. In order to analyse the complex problems around these questions we study discursive and political differences between Denmark and Sweden. In Denmark, it is possible for disabled people to get support to buy sexual services – in Sweden this would be a crime. How did these differences originate and what do they mean concretely for people with disabilities and for those who work with these questions?

One central tool of analysis is gender theory. Is it possible to interpret the Danish attitude to sexuality – sex as a human right – as a 'male' project? How are the differences linked to the different developments of feminism in Denmark and Sweden? This is one of the central questions we will discuss from a historical perspective. Another central problem is how men and women with disabilities think and discuss around their need or their right to sexual fulfilment, and finally how women and men in positions of power define those questions from a gender perspective. Jens Rydström, who is an historian, will study similarities and differences in how disability and sexuality has been dealt with in Denmark and Sweden from 1925 until today. The sources will be governmental reports, laws, and archival material and membership press from disability organisations and sex reform movements, as well as interviews with a number of key persons. Before the 1960s there was not much talk about sex in connection to disability, but more about autonomy and work. The sexual revolution in the 1960s opened the debate and in the 1970s seminars and workshops were organised around this theme both in Denmark and Sweden. But state policies regarding prostitution and the regulation of sexuality have been remarkably different in the two countries. The project will compare state policies and the attitudes from the disability organisations and the sex reform movements in Denmark and Sweden.

Don Kulick's social-anthropological project will consist of fieldwork in Skåne and in Sjælland, and contacts have been taken with curators, advisors, and group-living collectives working with these questions. In Malmö, we will cooperate with the RFSU clinic and with Gerd-Inge Brander, who is an advisor working with disability and sexuality. In Denmark there are state and private organisations working within the field, for example Pionerlinien, a private company working with sex therapy for disabled persons, and the pension Hulegården, a group living facility for adults with intellectual impairments. Its director Lars Nielsen strongly emphasises the rights of disabled persons to sexual experience. The fieldwork will consist of participant observation at such group livings, at courses on sexuality and at dances where people with disabilities meet others and each other. The participant observation will be supplemented with life stories and interviews with individuals and groups of people.

The oral presentation at the NNDR Conference will be a presentation of the project's aims and objectives, as well as some preliminary results from the historical part of the project.

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Studies in Ableism – a new partnership with cultural studies?

Stories are like maps that provide security so the user will not inadvertently turn off the road, go astray or navigate haphazardedly into areas unknown or secured for the sole use of other, alien inhabitants. Like the map, stories provide clarity about the journey taken and the road ahead. Studies in Ableism ('SiA') is a recent field of enquiry concerned with the processes and effects of notions of normalcy and anomaly (disability). Compulsory ableness shapes our imagination as to the forms of 'perfected' bodies and the kinds of mental and emotional capacities that are valued. Ableism is a map of a simulated territory that denotes the homelands of humanness and the dispensable beasts and changelings existing on the perimeter. Ableist landscapes communicate the values of culture and secure the transmission of the 'memory' of a body of people; a form of anamnesis that makes connections between the past, present and the future.

A chief feature of an ableist viewpoint is a belief that impairment is inherently negative and should, if the opportunity presents itself, be ameliorated, cured or indeed eliminated. What remains unspeakable are imaginations of impairment as an animating, affirmative modality of subjectivity. Developed from within the field of critical disability studies as well as broader insights drawn from gender studies and critical race theory; 'SiA' examines the ways that concepts of well beingness and deficiency circulate throughout society and impact upon economic, social, legal and ethical choices. An Abled imaginary relies upon the existence of a hitherto unacknowledged imagined shared community of able-bodied/minded people held together by a common ableist homosocial world view that asserts the preferability and compulsoriness of the norms of ableism. At an international level the primary focus has been on developing a theoretical exposition as ableism (Campbell, 2008.Jul; 2008; Hopkins, Hughes, McKie, & Watson, 2005; Hughes, 2007; Overboe, 1999, 2007). More recently however there has been the early beginnings of an applied approach to 'SiA', in the areas of sport (Howe, 2007, 2008; Jones & Howe, 2005; Wolbring, 2008e), nanotechnologies & transhumanism (Wolbring (2008a,b,c,d,f) and law (Baker & Campbell, 2006; Campbell, 2001, 2005).

'SiA' through its lineage in disability studies is able to make a significant conceptual and methodological contribution to research in cultural studies around the marking and making of difference. The approach of the paper is three pronged. Firstly it explores the problem of speaking/thinking/feeling - about the Other (in this case persons referred to as 'disabled people') and the 'extraordinary' Other, the 'Abled'. Here I argue it is necessary to shift the gaze of contemporary scholarship away from the spotlight on disability to a more nuanced exploration of epistemologies and ontologies of ableism. As part of this project of exposure the second task of the paper is to tease out the strands of "Ableist Relations", including the effects of the compulsion to emulate ableist regulatory norms. Finally, to make the necessary connections between theory and practice, the paper looks at the tasks ahead in the refusal of Ability and the commitment to a disability/not-abled imaginary.

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Caring capes of families with intellectually disabled children in Finland

The majority of people with intellectual disabilities have always lived in family setting. Within families, it has traditionally been the mother who has carried the main responsibility of the carework required to keep the everyday life going. However, the identity and status of the people with intellectual disabilities and their carers – both in and outside families – are under reconstruction due to the recent restructuring of the welfare state as well as more general social and economic processes.

In Finland there is a lack of knowledge about the effects of these changes in the lives of families with intellectually disabled children and how they respond to them. It is important to do national studies on this issue, as the restructuring of the welfare state takes different forms in different countries. It is also important to study restructuring of the welfare state from the perspective of different groups of people, as the policies towards them are likely to differ within the welfare states. Research on care of people with intellectual disabilities faces also important theoretical challenges. Feminist and disability studies have developed diverging approaches on care, and the need for developing a dialogue between them has been recently recognized.

This presentation portrays a new research project that aims to study the everyday lives of family carers and the intellectually disabled people they care for through an approach called "caring capes" (McKie & al. 2002), which has been developed to integrate the feminist and disability perspectives (Watson & al. 2004). This approach focuses on the paths that care givers and care recipients negotiate in multilayered contexts over time. The data of the study consist of life history interviews with Finnish parents who live in the same household with their intellectually disabled child. The presentation also includes a preliminary analysis of the collected material.

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Disclosure of impairment in higher education

Purpose
The purpose of this presentation is to discuss one aspect of the restrictions students with impairment can be confronted with in higher education.
The intention of the project "Disability and higher education" is to explore how students with impairments experience their everyday life. The main focus is to examine what restrictions they meet, and the consequences this imply for studies and for participation in a student life.
Higher education is generally regarded as important for young people. For disabled persons it is seen as one of the most important strategy to increase participation. With higher education a membership in the labour market increases between too and three times (Bliksvær og Hanssen 2006). To reach the governmental aims of an equal right to higher education, there are political agreements on the necessity of increasing accessibility to buildings, transport, information and communication technology, literature, counselling and support, social services, and to loan and scholarship to compensate for extra costs due to impairment and an extended period of study.

Method
To grasp the everyday life of the students the time geographic diary (Ellegård & Nordell 1997) is used, asking the student to record time in activities, places and social relations during one week. The diary illustrates routines and preferred activities in a social and geographical context, and indicates what can be restrictions for the individual. Diary writing was followed by a qualitative interview, where everyday life situations were deepened. Common themes that emerged during the interviews, were discussed in focus groups.

Results
Everyday life is shaped by what the individual give preference to, and by the restrictions met. The students in this study met restrictions in a number of daily activities, at the university, at home, when travelling and in contact with representatives of the welfare services. They spent more time than most other students in rest and sleep, in several ordinary daily activities, as well as in the struggle of making the study situation accessible. Restrictions can not only be seen as physical and technical conditions, but can as well appear in attitudes and behaviour. Students with invisible impairment have to make oneself known to increase accessibility, which involves a danger of being turned down. This presentation will discuss three critical situations where disclosure of impairment is necessary in order to make the study situation accessible; 1) when the learning environment, as a lecture or exam are inaccessible, 2) when using special equipment or technical aids, and 3) when working in groups together with other students.

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Accounting for a visit to the audiologist

Keywords: Ethnomethodology, Conversation Analysis, accounts, hearing impairment, audiology

This paper presents ongoing research into the methods hearing impaired persons and audiologists utilize solving problems brought to the consultation by the hearing impaired person. From an Ethnomethodological and Conversation Analytic perspective we explore consultations between audiologists and hearing impaired persons in a small, private hearing clinic in Denmark. Nine naturally occurring consultations of approximately ½ hour in length respectively were video recorded. The audiologist is the same in all cases, while each recording features a different customer. The recordings have been transcribed according to Conversation Analytic standards and subjected to sequential analysis. We present preliminary findings concerning how hearing impaired persons, as customers or potential customers to the clinic, and the audiologist interactively manage accounts of why the customer is seeking help. 'Accounts' refer to the methods through which the hearing impaired person offers reasons for their visit to the audiologist. Specifically our focus is on how such accounts are initiated, received and developed as well as what the accounts tell us with regard to how hearing impaired persons make sense of their impairment. From the audiologist's perspective, the accounts ostensibly serve to ground decisions regarding the service or product to be offered to the customer. And from the hearing impaired person's perspective, accounts are a way of presenting a problem requiring a service or product from the audiologist. A common example in our data is an account describing a failure to hear properly in some everyday activity followed by an adjustment being made to a hearing aid. It is important to note that both the account and the 'adjustment' are interactively managed by both parties. In other words, the impetus for and results of a consultation are socially managed. Thus,we will claim that analytic methods which focus on such data in terms of individual participants and their individuated actions, for example 'how audiologists give advice', will ultimately fail to account for the consultation as a lived, social practice.
NB: paper in symposium 'Micro-analytic social studies within Disability Research'

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Different definitions of disability and the impact on research results

In disability studies there have for decades been an ongoing debate on how to understand and define disability. As a consequence there exist several partly conflicting theoretical concepts or understandings. The aim of this paper is however not to address theoretical debates, but the methodological challenges that is raised when transforming theoretical understandings into operational definitions in survey research. Researchers have for a long time struggled to find a good operational definition of disability, and today there is no common agreement on this issue. Consequently, a variety of operationalisations is used in different studies. Definitions is likely to have an impact on outcomes, which is suggested the different estimates of prevalence rates of disabled people in for instance Norway or across Nordic countries.

This paper discusses how different definitions and operationalisations of disability can affect the outcomes in studies of disabled peoples living conditions. Three different types of definitions of disability are compared; subjective, administrative, and functional definitions. Various operationalisations within these three types of definitions are included. Analyses were conducted using data from a special survey of disabled peoples' living conditions in Norway, gathered in 2007. The empirical data contains a screening of 7632 people from a sample of 11 000 persons in Norway (age 20-67 years), and a main survey of 1652 people recruited from the screening sample.

Results from the analysis indicate that depending on definition, the prevalence rate of disabled people in Norway varies up to 20 percent, from 8 to 28 percent. The group of people classified as disabled differ between definitions, and this is likely to affect other research results for instance concerning disabled peoples living conditions. To illustrate this we present the influence definitions of disability have on employment rates among people with disability. As the employment rates vary according to definition of disability, it is concluded that it is a need for consciousness about how choice of operational definition may affect research results.

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Theatre nonSTOP; a theatre for art and empowerment

In this presentation we will describe an action research project; how to establish theatre as work for actors with mental disability. Our main purpose has been to develop our own knowledge in due to create a theatre based on empowered participants. Our work is based on the values empowerment, freedom and equal rights for all people. Not only as individualistic values for self-realization, but also as values of dignity and respect. Not the right to do whatever you want, but the right to be treated as a valuable human being. And the right to tell your own story.

As teachers and researchers for social educator students our concern is to develop learning strategies for how social educators can encourage empowerment. In this poster we will show the process working with a group of students, community administrators and organizers, and participants (actors) with mental disabilities. Our claim is that knowledge is socially constructed, and developing new strategies for empowering people have to be created in collaboration between implied parts. This project describes how we have established working places in a theatre for people with mental disabilities.

First of all, people with mental disabilities are often left out of many parts of the society, and lacks the possibilities that most of us have in choosing both education, work and leisure activities. The principles of empowerment often seems neglected or professionals finds them difficult to carry out. In Norway, since 1991, there has been an official strategy that people with mental disabilities should be included in the local communities with the same rights as all other inhabitants. This still seems to be a difficult task, because it\'s not enough giving the rights, the rights must also be implemented in practice. And to carry them out, both professionals and participants needs to learn how to do that. People with mental disabilities, as people with other disabilities, have often been stereotyped, and have had few arenas to examine and communicate their own stories to the rest of the world. So our concerns can be seen as 3 main goals:
•   develop a theatre based on empowering communication
•   establish an arena where students can learn how to participate in a dialogue based on empowerment and equality
•   explore how the participants can use theatre to tell their stories about the special experiences that often are left out in the public, both represented in the content of the plays, but also to show that this group of people can create excellent and innovative theatre

This project is based on the cooperation between the community council of Namsos, Nord-Trøndelag University College (HiNT), A co-operative work society for people that need adjusted workplaces(MN-Vekst) and The Norwegian Labour and Welfare Administration (NAV)

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Helge Folkestad, Bergen University College

A symposium on working with informants with intellectual disability

Conveners: Helge Folkestad, Bergen University College (N), and Õie Umb-Carlsson, Uppsala University (S)

The symposium in called to focus on methods. Experienced researchers from Nordic countries open the discussion by presenting their perspectives on the challenges, pitfalls and gains when information is sought from people with intellectual disability themselves. The subsequent goal of this symposium is to initiate, within the NNDR, a network that deals with these issues.

Speakers
Karin Barron, Uppsla University:
Ethical considerations in social research with persons with intellectual impairments: Drawing on a qualitative study on identity (re)constructions among Swedish women with intellectual impairments of different ages, the issue of ensuring confidentiality and individual consent is focused on.

Anders Gustavsson, Stockholm University:
New perspectives on self-image and identity: Experiences of persons with intellectual disabilities and how their own narratives can be used as data in exploring multidimensional and multi-categorical identifications.

Anna M. Kittelsaa, NTNU Samfunnsforskning AS, the Norwegian University of Science and Technology.
On the experience of combining participant observation and interviews with intellectually disabled informants during long-term engagement; the pros and cons.

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Anders Midtsundstad, Kristiansand kommune
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Leisure organisations are willing and able

The Norwegian Directorate of Health, by means of the national project "Leisure for All", wishes to strengthen the work in the field "Life assistant – culture and leisure participation" in Norwegian municipalities. One of the central challenges for the municipalities is connected to the continued development of cooperation with voluntary organisations. Meeting this challenge requires competence and new tools. Children, young people and adults with a disability are those who may need support from the municipality to achieve meaningful leisure. In this connection, using life assistants is a fundamental tool in reaching such an aim.

The life assistant service is a statutory provision which is intended to make it possible to achieve the ideals of an active and meaningful life together with others. For many of the more than 30,000 people with access to it, this service is decisive for their being able to take part in culture and leisure organisations they themselves have chosen. In this connection, the Directorate of Health suggests that the life assistant service can be organised in three main ways:
- individual life assistant
- participation in an activity group
- an individual arrangement in cooperation with a voluntary organisation

The starting point of the paper will be practice experience from the continuous development of this work in Kristiansand Municipality, where the method Supported Leisure (SL) has been tried out and developed by means of several projects from 1998 till the present. The method has been adopted in many Norwegian municipalities and represents a contribution when people, in their process of inclusion, seek support towards membership in an activity they themselves have selected.

In our individually oriented society no one makes a choice based on absolute freedom. Most choose on the basis of what is usual and considered acceptable. Ideals attached to the aim of "full participation and equality", which is an overriding sociopolitical aim, seem to build on theories of integration that emphasise a shared-value community. When Norwegian social policy lays such great emphasis on everyone being able to take part in the ordinary spheres related to culture and leisure activities, this has to do with the fact that not everyone in society has the same opportunities to realise their desires, needs and dreams in these spheres of life. Some people always seem to be restricted and we must recognise that society is characterised by a different degree of differences in interests.

Supported Leisure makes visible a work process in which a case worker in the mucipality and a focal member of a chosen leisure organisation can cooperate and complement each other in order to achieve the goals defined by the member of society who needs support in his or her process of inclusion. The paper focuses on experience based on cooperation with more than 100 leisure organisations in Kristiansand.

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Cultural Scapes, Older Age and Learning Difficulties: narrative accounts of living in the 'inscape of yesterday'

This paper explores the relationship between older women who are labelled as having learning difficulties and the physical and cultural 'scapes' around them. It draws on a range of individual and group narrative / oral history accounts from older women who are now located in an inner city area in the North of England. Their narratives demonstrate how environmental factors and locality shape how learning difficulties are perceived and understood, not just by the participants, but by others around them.

For example, participants had spent their early and teenage years living in institutions which were set apart from the mainstream of community and city life. In this respect, the women were socially excluded, but their narratives highlight a subculture 'scape' in which they forged a sense of identity. Several participants also had memories of leaving the institutions to 'work the mills' during the war years. This new 'scape' and sense of belonging to a wider community was short lived as they returned to the institutions when the 'men came home from war'. Later, Community Care initiatives saw the women again being transported back into a post industrialised environment, whereby the large factory units became home to the 1970/80s inner city day centres, and participants were 'deinstitutionalised' into smaller hostel-style spaces. Spaces which were once again located on the margins and 'set apart' from the city. Despite efforts to promote integration the participants in this study remain in a position of being socially excluded in their environment and locked into their scapes of yesteryear.
In conclusion, the themes raised in this research project highlight how the disabled body is not only socially produced, but environmental factors, 'scapes', spaces and places are equally as influential in supporting or challenging this construction.

Key words: Older age, learning difficulties, gender, social exclusion, environment, scapes, identity, UK

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Ethics and moral in service system for children with FASD

FASD (Fetal Alcohol Spectrum Disorder) is a main specific cause of intellectual and developmental disabilities in today´ s Finland. Those children that have been affected by alcohol before being born have many problems in their later lives and less opportunities than other children. In many cases those children have worse living conditions than others with different economic, social and health problems in their families. In order to provide best possible living conditions to them, it is necessary for professionals to encounter their problems as early as possible. Still in many cases, the reason for failing to recognise child´ s needs depends on personal attitudes of the professional towards this problematic.

Aim of this paper is to discuss, what are the moral and ethical principles in accounts of those professionals who work in the social service and health service system with children with a diagnosis of FASD (Fetal Alcohol Spectrum Disorder) and how they construct their position as professionals in those accounts. The data is in the process of being gathered in social service and health service sector in three counties in Finland and it will contain 30-40 semi-structured interviews among the professionals. Discourse analyses will be used as research method with positioning theory as a specific starting point. The interview accounts will be analysed by investigating certain "valuing" positions and discourses concerning personal work with FASD – children.

In this early stage of data gathering, it seems that in many cases those persons with professional experience with children with FASD – syndrome must recognise contradictions in their professional ethics in working with those children and their parents. In professional settings it is not appropriate to make judgements on the life situations of those families, although their personal opinions may be harsh and condemning towards those mothers who drink in the course of their pregnancy.

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Intellectually Disabled as a "Competent Citizen"? Discussions on methodological challenges in studying discourses on special paths in vocational education

Institutional education is a national project aiming to produce good and competent citizens. In Hakala's on going research the focus is on the vocational education and training (VET) for intellectually disabled people. Finnish national curricular documents use the concept of "competent citizen" to describe the goals of VET and a strong aim in educational policy is that all citizens get a degree in post-compulsory education in upper secondary level. The idea of a competent citizen and possibilities for intellectually disabled people to fullfill that idea constitute a complicated field of study which goes into very profound questions of a good life and social justice. Prevention of social exclusion has been a recurrent theme of educational policy ever since the enlightenment ideals of schooling as state organised institution of wealth and wellbeing of citizens. Lately the theme has been intertwined with the ideas of lifelong learning, neo liberal ideals of global competition and the economic effectiveness of labour markets. Also in resent tendencies the disabled people have been taken into account as one potential solution to the imminent labour shortage and new ways of employment strategies for those who are "badly employable" have been mobilized.

The field of the vocational education and training in Finland is under a change process in their governing organizations. The special vocational schools that has thus far been under the maintenance of the state are to be transferred to the maintenance of five private associations for public good which has been organising vocational special education and training. Three of these schools are institutions that have long traditions in organising education and training for people with intellectual disabilities. Hakala is following and documenting this change process by asking what is happening for the meanings of the concept of "special" and how the category of intellectual disabled is changing, or is it changing in this process. The research questions are 1.) what kind of citizenship is possible for the students who have been defined as intellectually disabled and as such in need for special education 2.) what kind of differences actualise in the process of defining those possibilities. By asking these questions the study aims to explore such controversial ideals in special education as social segregation, integration and inclusion: how they are practiced in vocational special needs education and training for intellectually disabled and how they intertwine with the caring and governing practices in the social service system for intellectually disabled people and their families.

The research data consists of educational policy documents, curriculum texts and interviews with professionals working in the field. The methodological challenges in the study intertwines personal perspectives and the questions of scientific knowing as Hakala is a mother of 19-year-old daughter with Down-syndrome. A feminist poststructuralist approach is applied in the study.

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Disability status and population ageing

Disability status in later life between older people who grew up with impairments and those who acquired them later is the core of the paper.

We live in an ageing society and the increase in world population ageing is dramatic. In general terms, the proportion of people aged over sixty is predicted to rise from 10 per cent in 2000 to 28 per cent during this century. Medical, technological and social developments mean that there has been a dramatic increase in the number of young disabled adults who survive into old age. The increased longevity of people with long-standing impairments raises questions about the ways in which societies respond to disability issues amongst ageing populations. Global population ageing, including the increased life expectancy of younger disabled adults, means that we are already witnessing a substantial increase in the number of old disabled people, and that we may expect to see this trend continue. This calls for a specific attention to reframe social policies and institutions in response to changing population needs. But such analysis tend to construct the problem of disability only in terms of 'health' and 'functioning', viewing 'disability' only in terms of individual impairment and physical functioning, rather than environmental limitations or disabling barriers.

The issues and debates are then about the extent that the growing population of older disabled people can be included in discussions of disability rights. If disability policies and debates continue to focus on adult issues, such as employment, then there is a danger that an increasing number of older disabled people will be further marginalized and excluded, because old age is a time beyond employment.

Although the presence of impaired bodies in childhood, youth or adulthood creates tensions with the embodied norms of those generational identities, the prevalence of impaired bodies in old age appears much les disruptive of traditional ageing identities. The generational context of impairment is a very significant factor, one that has been consistently overlooked in both sociology and disability studies. Late life impairment may appear less disruptive to the biography and identity of older people than to those of younger people, because the normalcy of impaired bodies in old age, and particularly in advanced old age, may help to explain why older people with impairments are rarely regarded as 'disabled' in the same way that younger adults and children are.

The paper is focusing on a lack of cross-over between critical studies of ageing and critical studies of disability. The research question focus on the constructions of bodily impairment and disability identity as generationally situated.

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My opinion, my vote – MOTE

There are various barriers preventing people with learning disabilities from taking part in democracy on equal terms with others. The Equal Opportunities Centre for Disabled Persons is part of a EU-funded project "My opinion, my vote – MOTE". The aim of this project is to make people with learning disabilities aware of their political rights.

The Italian organisation for people with Down's syndrome (AIPD) is the principal organiser and participant in the project together with Fundacio Projecte AURA and Universitat Ramon Llul from Spain, Sio2 from Italy, Down Syndrome Ireland, Dowm Alapítvány from Hungary, University of Malta and Equal Partners from Malta. In connection with the project an advisory group of four persons with learning disabilities have been appointed from each of the six participating countries. They will participate in all phases of the project.

The presentation will focus on the results of two surveys to be made in the beginning of 2009. The first survey will provide factual information on political rights and good practice with regard to teaching democracy and political rights in each participating country. Besides, interviews will be carried out among twenty persons with learning disabilities. The aim of the interviews is to throw light on their experience with political participation and voting, and how to acquire knowledge about voting and political party programmes.

Keywords: Democracy, political rights, people with learning disabilities, experiences with voting, good practice on teaching democracy and political rights.

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Pioneers in the Modern Disability Movement: A Political Life Course Perspective

The overall aim of the project "Disability, Life Course and Ageing" is to study disability and ageing from a life course perspective. The more specific aim for this paper, "Pioneers in the Modern Disability Movement: A Political Life Course Perspective", is to investigate and discuss how some of the most important activists in the Swedish disability movement reflect upon their involvement in disability politics from the 1960th until today. The goal is to find out more about political ideas and the struggle for disability politics and reforms, especially against discrimination. For this purpose two methods has been used: qualitative life course interviews with important people in the disability movement and studies of texts written by the same category. The choice of informants is based on three criteria: personal long-term experience of impairment; political top level work for questions concerning disabled people and an age over 55 years old.

The research of disability political history, ideas and reforms has not been very inclusive so far. One goal in this study is to start from and discuss disabled people's perspectives, insights and point of views, i.e. their picture of modern disability history. Preliminary results indicate that older disabled people in Sweden can look back on several rather complicated ideas and reforms, of great importance for their individual life course. One example of such a revolutionary experience is the law from 1993 about support and services for disabled (LSS), which is described as the most important turning point in disability history in general and also in one's own personal life.

Political activism and work for questions concerning disabled people is a way of living for the people involved in this study. Reflections upon one's life course are affected by success as well as disappointment. In the light of disability history, norms and ideologies, there shouldn't be any differences between disabled and non-disabled, but history "bites" and influences the narratives and reflections. As a result of this study some important dilemmas of disability history and the life course of disabled people can be described and discussed. One important dilemma, for example, is the struggle for a "normal" life course containing education, family, work, ageing and later life on the one hand, and the fight for specific rights, laws, resources and disability "pride" and acceptance of difference, on the other.

The study is part of a research program, "Disability, Life Course and Ageing" which is financed by the Swedish Research Council, and consists of 4 studies: 1) "Disability, Life Course and Ageing – a 25 Year Perspective" (Professor Eva Jeppsson Grassman), 2) "Family, Ageing and Disability" (PhD Anna Whitaker), 3) "Pioneers in the Modern Disability Movement: A Political Life Course Perspective" (PhD Lotta Holme) and 4) "Disability, Age Norms and the Lived Life" (PhD candidate Annika Taghizadeh Larsson).

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Food and the lives of adults with learning disabilities: discussing food, health and obesity

Obesity is subject to growing public interest and there is increasing pressure to achieve a 'healthy' body weight. There is evidence to suggest that the prevalence of obesity amongst the learning disability population is greater compared with the general population. Further, although the occurrence of obesity in the general population increases with age this is not the case for the learning disability population. This suggests that this group are at risk of obesity from an earlier age, possibly meaning that they are also at earlier risk from the onset of obesity related disease.

The factors influencing food choice are complex and while issues influencing this have been investigated in the general population there has been limited work with adults with learning disabilities. Previous research has focussed on health knowledge and ignored the context within which choices take place. While much work has been done on the experience of having a learning disability little work has looked at the feelings and perceptions people with a learning disability have about their physical selves.

This paper will present research findings from an ongoing PhD study examining food choices of adults with a learning disability. The data are based on a series of semi-structured interviews, and focus groups with people with a learning disability in Glasgow. It will use these data to explore the factors that effect food choice, including the opportunities available to make decisions, individual motivations and the influence of others. Attitudes towards healthy eating will also be examined. The final section will look at health beliefs, including actions associated with promoting health and notions of control over health, and feelings about weight and weight loss. These will be examined alongside wider issues concerning control and autonomy. The paper will focus on links between attitudes towards food and thoughts about health, and the interaction between health and diet whilst considering the extent to which adults with learning disabilities are able to exercise autonomy and control.

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To reach university studies or not – youth's voices

The life between youth and adulthood is important and seems to constitute a longer and a more and more risky period. It's a period of crucial importance to future developments and could either lead to lifelong dependence or lifelong independence. This transitional phase hosts a lot of challenges in general and plays a decisive role for youths with disabilities, both from an individual and a social perspective. With a starting vision of "a society for all", the intention was to study how such a vision could be integrated on University levels, in what ways all individuals, with capacity for university studies, are expected and welcomed. The aim of the study was to highlight social participation in the phase between upper secondary school and university, putting an emphasis on responsibility and involvement. A lot of phenomena from micro- to macro levels in this complex period, will implicate a theoretical framework which have connection points with social responsibility at different group levels.

Focus on responsibility and involvement in relation to study conditions has been studied undivided from the students' point of view. The project started with a quantitative national study, in order to recognize to what extent youths with severe physical disabilities with qualification for University studies, actually goes through with them. The results implicate to go further on with a new methodological starting point. To determine this completion, entirely on the students' view, interviews were carried out in a manner that encouraged a smaller study group to be narrative. The outcome shows a varied view. Different cooperation skills influence the individual's prospect to participate in higher education. The first part of the study shows for example that two thirds with adequate knowledge from their upper secondary school have not gone further on to university studies between 1 to 5 years after they completed their upper secondary school studies. In the second part, the analysis of the interview material, the condition for the responsibility falls out in three themes: how responsibility appears, is distributed and in what phase necessary measures take place. To illustrate the theoretical qualities, four fictitious persons were portrayed. Eugen, Ian, Nora and Buck illustrate and exemplify how they experienced the collaboration between different levels on their way to reach, or not to reach university studies.

The tentative conclusion of the study shows the value of cooperation, the value of dividing responsibilities and the value of continuity. Taking care of, and build on students' experiences, interrelated with both humanistic and democratic values. It seems as a powerful effort in this phase, could on a longitudinal basis be a favorable investment in a young generation, as well as for a society as a whole.

Key words: narratives, transition, university, voices, youths

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Follow-up of cochlear implanted children; some bioethical aspects regarding choice and precaution

Since 1998 the Norwegian Educational Act (Section 2, 6th paragraph) has asserted deaf children's legal rights to acquire both Norwegian Sign Language as well as spoken Norwegian.1 Such bilingual education is recommended both by the Norwegian Deaf Association as well as by many professionals working with deaf children. In January 2008 it became publicly known that Rikshospitalet University Hospital advises parents of deaf children who receive cochlear implants against this bilingual approach and instead recommends monolingual habilitation through "auditive verbal/oral training".2 The development of speech is the objective of such habilitation, and sign language is recommended only as a secondary option for those children who fail to develop speech. As these two doctrines prescribing how best to follow-up a cochlear implanted child are mutually exclusive, the parents responsible for choosing between one of the two alternatives on behalf of their child are faced with a choice that might have bioethical implications. The present paper seeks to analyse if such bioethical aspects exists and if they do, how they could be dealt with. On the basis of a historical analysis as well as a review of the existing research on outcomes of paediatric cochlear implantations, I conclude that there might ethical problems involved while choosing follow-up: Historically, attempts of habilitating hearing impaired children monolingually with speech only have 1) not been very successful and 2) conveyed the message to many of these children that they were unauthentic and inferior to hearing people. Cochlear implants no doubt represent a breakthrough as assistive technology for deaf people. Still, research shows that variations in outcome are still high, and a large percentage of the variation is unaccounted for. Hence, we can not rule out the possibility that some implanted children have a less than optimal outcome of their implants, thus resembling the earlier generations of hearing impaired children mentioned above. I suggest putting forth a precautionary principle as a practical solution to the possible problems the parents might be facing. Although scientific uncertainty exists in the case of both doctrines, there is a scenario of possible irreversible harm to some of the children habilitated monolingually. An application of the precautionary principle hence suggests that one should agree on the bilingual approach, at least for the time-being.

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Expert or lay perspective: alternative assessment processes to understand disability in the Norwegian welfare state

Abstract

This paper discusses definitions and assessment procedures for conceptualising disability in current Norwegian welfare state. Modern welfare states, like the Norwegian, distribute welfare provisions and service programs to people with disabilities. The assessment procedure and decisions about disability may and do vary in these programs. In the paper I discuss two distinct and different alternative assessment processes to understand disability: the expert assessment or lay and self-directed assessment procedure. The paper relates both to the use of own facet, demarcation lines and underpinning principles for how to give meaning to the disability concept in the expert or lay perspective. It also relates to appearing principles in current Norwegian welfare state as concern disability policy. In particular how definitions of disability are adjusted and coordinated to EU and the directive of equal treatment for people with disability (FETD Directive 2000/78). The paper argues that the Norway welfare state is a context interesting to study understandings and assessment procedures to disability as a phenomenon. This as Norway has a well-equipped provision programs and measurement and some of them have long historical traditions in welfare policy. Others are a result a new reforms and decision-making in disability policy. Though Norway represent an advanced welfare state model in the terminology of Esping-Andersen, it debated if some programs use more primitive instruments and classification criteria for decided about eligibility to disability programs. It is interesting to explore what type of welfare programs allow for the lay perspective to disability, and what type of programs to not. In addition the paper analysis how these alternative ways grasp the meaning of disability differently and construct new paths of dependency for how a person with disability can address welfare state provision.

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Pedagogical praxis – an example from special schools for pupils with moderate to severe learning difficulties.

This paper will present some findings from my ongoing work with my doctoral thesis. The study deals with questions about learning and socialization in special schools for pupils with moderate to severe learning difficulties. The overall aim is to study the interaction between pupils and teachers and describe the patterns, forms and content in their vocal- and non-vocal interaction in the classroom. A point of departure is that learning occurs in a social context and in collaboration with others, and the theoretical framework in the research is inspired by a socio-cultural perspective and an interactionistic perspective . My specific research questions are:

• What kind of patterns appears in the interaction between pupils and teachers in the classroom?
• What kind of learning- and socialization processes appears in the verbal- and non-verbal interaction between pupils and teachers?

The design of the project is inspired by an ethnographic approach and is constructed as a classroom study. In all, three different classes participates in the study and the pupils in the classes go to the compulsory special school for the moderate to severely learning disabled (särskola/träningsskola), aged between 8 and 17 years.The empirical material is collected by participatory observations, by video recordings and by interviews with the teachers and the pupils. The video recordings are analyzed using techniques derived from what Scheff calls a part/whole analysis. The process of analyzing one of the classroom studies is in progress and the findings so far will be presented in the paper.

Keywords: classroom study, pupil and teacher interaction, pupils with moderate to severe learning difficulties

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University education for people with intellectual disabilities

One of the programs offered today by the University of Iceland is a two year inclusive semi professional program for students with intellectual disabilities. The program is organized as a two year research based developmental project and it is situated within the division of social pedagogy. It started in the fall of 2007 and the enrolled students will graduate in the spring of 2009. This is the first time that such a program is being offered in Iceland. The aim of the study is to enable the students to graduate with the knowledge, skills and values that will let them take their place confidently in various jobs within the field of social pedagogy. As well as to ensure the best practices in supporting people with intellectual disability towards full membership in society. In this lecture the focus will be on the research and the vision which formed the bases for the development of the curriculum as well as on the key issues that guided its implementation. Special emphasis will be on the curriculum itself and inclusive teaching methods within a university setting as well as collaboration with work placements in the community. This research is still ongoing and in this paper the first results will be presented such as the evaluation of the aim, structure, main components,inclusive teaching methods such as the model used for support system wihtin university classes. At last the light will be shed on personal outcomes for the students with emhpasis on empowerment, leadership skills and full paricipation.

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Adapted Physical Activity in a municipality in Denmark

Introduction: Municipalities in Denmark are responsible for health promotion and prevention of disease. It is therefore crucial that citizens have access to physical activity in their local community. For people with disabilities there are certain limitations for participation in physical activity, e.g. physical inaccessibility, lack of information of suitable activities. A municipality decided to make options for disabled people to participate in physical activity. Objectives: To ensure that everybody, irrespective of functioning, can participate in physical activity in his local community and that the municipality can rely on these activities in health promotion and prevention of disease. Method: A coordinator of APA was hired for one year. Her main task is to guide people into APA activities, assist in creating new activities and make information about APA accessible for everybody. A survey of organizations who provide APA was elaborated. Interviews were made with the instructors to reflect their competence in relation to health promotion and prevention of disease. Interviews were made with key-persons in the municipality administration to point out their expectations to the organizations in relation to health promotion and prevention of disease. Results: Results up till now point out that human and financial support to organizations providing APA is needed, bridging between private, voluntary and public organizations is needed, and education of instructors in APA is necessary.
Conclusion: Many organizations want to provide APA to disabled people and contribute to health promotion and prevention of disease. This project will reveal what is needed to elaborate and qualify these options.

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"I have so much to say" Life histories of Icelandic people with intellectual disabilities in the 20th century

The voices of people with intellectual disabilities have for the most part been absent in Icelandic history. Instead, other people have spoken on their behalf and described their lives. The research presented in this lecture explores the hidden history of people with intellectual disabilities and provides a space for their voices. The research is based on eight life histories of people with intellectual disabilities born in the first half of the 20th century. Other participants included their siblings and staff members from the disability service system. The aim of the study was to gain knowledge of the everyday lives and experiences of this group of Icelanders and explore their self understanding. In particular, I have examined the ways in which the scientific knowledge and the dominant ideology about people with intellectual disabilities have shaped their daily lives, identities and possibilities. The study is framed within the qualitative research tradition and data were collected through interviews, participant observation, focus groups, and document analysis. A research group was also established as a part of the research process. Participants in the group, besides me, were four of the life historians. The work in the research group was based on the inclusive research approach where the participants with intellectual disabilities are close collaborators and involved in all stages of the research process. The findings of the study indicate that the difficulties encountered by the participants were primarily created by the negative and stereotypical understanding of intellectual disability rooted in eugenic arguments and the medical view of disability. These approaches to disability created the basis on which the participants were treated by the larger society and the majority of them were removed from their families, often at a young age, institutionalised and segregated from other community members. The further influence of these attitudes resulted in the sterilisation of most of the women and very limited or no formal education. The findings also demonstrate that despite often humiliating, abusive and difficult circumstances, research participants emerge as resilient and strong persons who have survived these negative experiences. The participants do not portray themselves as victims but as survivors who have resisted and fought against the discrimination and inequality which has dominated much of their lives. As a result, emerging from the life histories is a new image of people with intellectual disabilities which challenges the dominant and negative stereotypes about this group of people.

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Employers' motives and incentives to employ persons with intellectual disability

Keywords Intellectual Disability, Work, Workplace Integration, Acceptance.

Background: Persons with intellectual disability experience difficulties to get or maintain a job in the open market. However, some employers hire disabled persons for various reasons. More knowledge is needed about employers' motives, considerations and experiences.

Aim and research questions: The aim of this study is to investigate and describe employers motives, incentives and considerations to employ a person with intellectual disability.

Metod: The investigation was conducted with qualitative research methods: case studies, observations, conversations and interviews.

Result: The result indicates different motives. Firstly, employers in private sector point to economic motives, or to the fact that taking care of a disabled employee is very time-consuming compared to what they get in return. Technical aids may sometimes also be required. Secondly, employers may have production motives, i.e., suitable worktasks that the person can perform. Thirdly, employers may have social motives, indicating that the person contributes to a "good workplace atmosphere". Social motives also encompass values, such as solidarity or a willingness to give an intellectually disabled person a "fair chance" in working life.

Employers in public sector put less emphasise on economic motives, and instead emphasise the importance of having or creating suitable worktasks. They also argue that if intellectually disabled persons get suitable worktasks this might facilitate work for other employees because of "more hands", "slower work pace" and better quality of work. Public employers also express the same social motives as private sector employees.

Employers in voluntary sector emphasise altruistic caring as a key motive and the willingness to support players in the local community. They share the same social motives as held by private and public sector employers.

Discussion: The result indicates the importance of a functional support system for both employers and persons with disabilities at the workplace.

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Construction of disability in World Health Organisation's classifications: changes and continuities

This presentation offers a social constructionist reading of two widely known classifications of disability: International Classification of Functioning, Disability and Health (ICF, WHO 2001), and its predecessor, International Classification if Impairments, Disabilities and Handicaps (ICIDH, WHO 1980). Both classifications can be used for a wide variety of purposes: data collection, education, clinical work as well as planning, implementation and evaluation of social and health care policies. But they are not simply the kind of neutral, objective tools that they may seem at first sight.

According to the philosopher Ian Hacking, there is a two-way interaction between classifications and people they are intended to describe. Classifications can help new classes of people to come into being in the course of history. In other words, the shifts in the social position of people with disabilities, the knowledge about their condition as well as the institutions around them makes them different kind of people in different times and places. Classifications of disability, in turn, have emerged at the same time as the groups of people to fit these classifications. Furthermore, this process is, as Hacking acknowledges, intertwined with relations of power.

The focus of the presentation is on the knowledge base of the ICIDH and ICF classifications. ICIDH classification was criticised for endorsing a medicalised view of disability, in which the problems of the disabled people were seen to be a consequence of their impairments and the barriers they face in their environment were ignored. It has now been replaced with the ICF classification, in which there is an explicit attempt to take distance from the medical model and develop a holistic view of disability that is called a "biospychosocial" model.

In this presentation a distinction is made between "surface knowledge" and "depth knowledge". They represent different forms of discourses: while surface knowledge consisting of things that are said, depth knowledge is not explicit and not necessarily even conscious. However, the meanings of the statements on the level of the surface knowledge are dependent on the depth knowledge. The presentation shows that while the on level of the surface knowledge about disability there seems to be a break between the ICIDH and ICF understanding of disability, on the level of depth knowledge continuities can be identified between them. Normalisation, objectification, quantification and biologisation are argued to be shared features of the classifications.

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Higher Education for Everybody?

The aim of this paper is to investigate and discuss some of the dilemmas of higher education, which might arise when there are disabled persons among the students. The focus of the project is university teachers attitudes to, and experiences of, teaching disabled students. One important goal is to find out and analyse variations in attitudes and experiences on a praxis-oriented level.

In Swedish higher education important democratic changes are taken place today, whose purpose is to make university studies possible also for disabled people. During the last 10 years more students with special needs participate in higher education, but the under-representation of disabled people studying at this level is still a problem.

To find out how university teachers look upon this questions 4 group interviews has been done with groups consisting of 4-6 experienced teachers at Linköping University. Important concepts, given in advance, were discussed by the participants during the interview sessions. The concepts were: quality, justice, disability rights and the Swedish discrimination laws. In addition some more questions were asked about possible alternative ways of working, changed teaching strategies and different methods for examination. From these interviews some preliminary conclusions have been made.

One important issue is the meaning of and content in the specific concepts mentioned above. There are some problems for the informants trying to define such complicated terms and to interpret their different meanings. Another observation is that a lot of knowledge is tacit and has not been formulated in words before. Some of the results point out that discrimination laws are of great importance for praxis as well as attitudes, both positive and negative ones.

One important dilemma is the relationship between quality and adjustments of examinations and teaching methods. There are also dilemmas related to student groups, both positive and negative, especially when it comes to problem based learning and justice.

University teachers are reflecting upon their own preoccupations but also over changes in politics and practice over the years. What is considered to be normal in one historical and cultural context might not be normal in another. The composition of student groups due to class, sex, age, ethnicity, religion etcetera is not the same now as it were only twenty years ago.

The way of thinking among the teachers involved in this study is the social model way, which seems to be quite spread today and inspire and persuade more people than experts on disability questions. But disabled students are not discussed in a systematic way in educational courses for university teachers at Linköping University and there is still very little Swedish as well as international research on this subject.

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Inclusion of an intellectually disabled person in academic work: contributions and shortcomings.

Dignity and self-respect in Norway is closely knit to a person's ability to maintain autonomy in everyday life and 'be the boss in your own house'(Gullestad 1984). Likewise, in a Western cultural view, a social person is respected for his autonomy and individuality (La Fountain 1984). But it has been claimed by for example French (1993) and Oliver (1993), that when it comes to people with disabilities, a heavy focus on passing and independence in everyday life can lead to stigmatisation and represent a problem for the fulfilment of other goals in life. Following this, the paper argues that the acceptance of need for help in some situations of everyday life, can lead to a richer life in total. One of the authors of this paper is defined as having an intellectual disability and receives help from the welfare state. In the last five- six years he has lectured students at the health- and social care study at the University College of Lillehammer, on everyday life as a person with mental disabilities. In these lectures it has come forth something which we, following Taylor, may call strong evaluations (1985). That is the judgement of some basic values in life which in short, say something about who you are as a person, I.e. social identity. In this case it is professional help to manage economy and the maintenance of decent living conditions. These choices, challenges cultural views of independence and autonomy, and also seem to be significantly different from the emphasis that Edgerton's interviewees placed on passing (The Cloak of Competence 1956). We also argue that the lectures of an intellectually disabled person, in this case, has contributed in important ways to student's preparations, as well as professional helpers reflections over the limits of what one needs to know about a person in order to help him.

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Welfare in the municipality – who is responsible?

Focus in this paper is on how to study implementation and transformation of local and national goals within public health, social work and the disability areas in Swedish municipalities. The paper will discuss the methodology of a pre-study which starts in January 2009. The municipality has the responsibility of the wellbeing and welfare of its citizens according to the national laws. In Sweden the local government is quite strong and the municipality has freedom to organise its work according to its own pre-requisites. The methods of the study are participating observations, interviews and content analysis of documents. The participants are local politicians and officials in leading positions within the municipality. The aim of the study is to make a better understanding of how politicians and officials reason about the need for new knowledge in the local government. What can we learn about the relations between research and practice?

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Understanding the quality of life from the perspective of people with intellectual disability

Aim: In the field of intellectual disability, the quality of life (QoL) approach is frequently used and great many research studies are presented in the literature. Typically, the fundamental nature of the phenomenon QoL is defined by the researcher. Empirical studies describing the essential constituents of QoL from the perspective of people with intellectual disability are scarce. Including the view of people with intellectual disabilities themselves adds richness and improves our knowledge and understanding of the phenomenon QoL.
In this study we strive to trace out the general essence of QoL by understanding the structure and meaning of the phenomenon from the perspective of adults with intellectual disability.
Method: For the analyses a qualitative approach inspired by phenomenology was used. We interviewed 21 adults with intellectual disability on their lived experiences of QoL. Because the effort was to catch rich descriptions, the coice was to include informants with varous life situation (gender, age, functioning limitations, civil status, ethnic background, housing etc).
An interview guide was developed in order to elicit breath and depth in responses and to make sure that all interviews explored experiences in different life domains such as housing, finance, social relations, personal safety etc.
Results: The findings indicate that the essence of QoL is to experience emotional, physical and social well-being. Five themes constituting this essence were identified: (1) social adult status, (2) personal safety, (3) empowerment, (4) social belonging, and (5) self-chosen solitude. The general structure of the phenomenon QoL found in the analysis will be presented and discussed in terms of the essence and the five themes.
Conclusion: The findings make visible the authority of significant others (particularly staff members and family) and their impact on the lived experience of well-being.

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User Involvement in Swedish Health care planning

Collaboration between user organisations and executive administrations is regulated in the Health care act §8. The concept is that users can contribute with knowledge and experience that is beyond the scope of traditional planning. Models for communication are developed and implemented. Research question is whether these applied models answers the intentions of the law.

Research method is content analysis with three approaches: 1. Interviews with representatives from user organisations, administrative personnel and politicians concerning their understanding of the concept "collaboration". 2. Study of minutes from meetings in Stockholm County 1996-2008 extracting themes and specific issues. 3. Study of four formal evaluations of different models used over this period. The results are compared by triangulation.

Results show that models are unwieldy, but that the more formal models give more opportunity for real exchange. Whereas personnel understand their responsibility as to give information either about memorandums on the agenda for the next political board meeting or returning themes such as budget reports or ongoing special studies, user organisations want to be involved early in the processing of issues. The users have difficulty bringing up issues; they tend to react more than act from their own agenda. They also have problems keeping the issues to overall planning and not related to specific diagnosis´ or interests. Areas where collaboration is effective and appreciated by all involved relate to specific, clearly defined issues such as development or distribution of technical aids.

What can be seen is that there is still a long way to go before fully successful collaboration is achieved. Some of the problems relate to traditional political forms which hinder the early contact and longer process desired by user organisations. Existing models for communication with union representatives affect the collaboration process in Stockholm County.

Key words: collaboration models, handicap/patient organisations

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Inaccessible ICT – a threat to societal participation

Objective/Purpose: Information and communication technology (ICT) is ubiquitous in modern society. The spread of technologies like the Internet and mobile phones have to a large extent affected the way we communicate, socialize, perform common tasks and the way most of us work. Access to and mastery of ICT have become vital for the ability to function as fully integrated citizens. Poorly designed and inaccessible ICT can lead to the exclusion from societal participation. Ideally all ICT should be based on the principles of universal design allowing for use without the need for individual adaptations and special equipment. Unfortunately ICT is rarely universally designed, and inaccessible ICT solutions are commonplace.

With this as a background we have conducted a study in which we have examined to what extent ICT in Norway is designed in a manner that allows easy access and usage for persons with disabilities, and to what extent mainstream ICT solutions are interoperable with assistive technology (AT).

Method: Our approach was tri-faceted. Firstly we performed a literature review of relevant material documenting the state of accessibility to ICT in Norway. Secondly we conducted an interview sub-study consisting of 21 in-depth interviews and two focus groups. The informants were professionals either working in the field of ICT, AT, accessibility and universal design or representatives for NGO's. An analysis was conducted to synthesize over arching categories and explanatory models. Thirdly we commissioned an accessibility evaluation of 12 popular Internet web services. The criteria used for the evaluation consisted of the principles of universal design, internationally recognized accessibility standards and interoperability with AT.

Results and Conclusion: The literature review revealed that there is a lack of documentation of how accessible ICT is in Norway. The main findings from the interview study showed that there are an abundance of concrete accessibility problems for disabled people when trying to use ICT. There are multiple factors explaining the existence of these barriers – the chief ones being a lack of awareness and expertise of the needs and design requirements for disabled users among ICT developers and procurers; a lack of legislative measures enforcing the design of accessible solutions; competency and organizational issues in the provision and follow up of AT and a technological development focusing on technological innovation rather than usability and user-friendliness.

The web accessibility evaluation indicates that universal design was not an issue when the services were designed, and that accessibility standards are only somewhat adhered to. The interoperability with AT is variable but borders on poor to medium. Overall there are a number of serious accessibility issues making use of these services burdensome for people with disabilities.

Despite the fact that ICT has given people with disabilities many new opportunities in terms of communication and access to information, there are a number of serious accessibility issues denying many people equal access to and the use of ICT in Norway. This is severely restricting societal participation for people with disabilities.

Key words: ICT, accessibility, AT, disability, participation   E-mail: oystein.dale@nr.no

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Getting rid of the changeling: Disability in Icelandic folklore

Aim:
It is a well known belief that the stories of changelings in the old western folklore are actually about disabled children. These stories do not only discuss the changelings but also the society that they lived in. The aim of this paper is to explore how the society reacted to the changelings in the old Nordic folklore and compare it to how western societies have reacted to disabled children through history to modern times.

Method
Discourse and content analysis were used to analyse changeling stories in the old Icelandic folklore and law, policy, media coverage and other written documents about disabled children. The analyses were guided by different perspectives on disability that has had influences on how disability is understood and reacted to.

Results and conclusion
New ideas can only be understood in historical and cultural context and the way we as society react to disabled children does have old roots. The old changeling stories are about who we are, who we welcome in our society and whom we reject. Although the changeling stories in the old folklores are about the 17th and 18th century society they have many things in common with modern Icelandic and Western societies.

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Parents and professionals working together

Aim
The aim was to explore the working relationship between parents with intellectual disability and practitioners. Special emphasis was on identifying what characterised a good working relationship and what helped or hindered that relationships from happen.

Method
The paper is based on a study on family support services for families headed by parents with intellectual disabilities. Data was collected through interviews and observation. Eight families and all their professionals and non-professional support workers participated in the study (in total 76 participants). The analyses were based on the approach of grounded theory and guided by social understanding of disability and interpretive theories of social structural realities.

Results and Conclusion
There was a great variation in the quality of the working relationship between parents and practitioners, quality that was first and foremost affected by the way practitioners understood disability. In western culture there is a tradition of understanding disability from medical perspective. This commonly held belief structure mirrors prevailing stereotypes of disabled people as inferior and childish. This type of understanding prevented practitioners and parents with intellectual disability from having a good working relationship as it worked against the parents' self-determination, made it difficult for the parents to define themselves positively and to trust their personal support worker.

Although the dominant social and cultural view of people with intellectual disability did affect the relationship between parents and practitioners, individual workers also brought with them their own individual perspectives, experiences and personal values which they applied to the families. Good and enabling attitudes and relationships was characterised by an inclusive approach, co-operation, flexibility, kindness, responsiveness and respect. This served to bolster the parent's self determination and positive feelings about themselves.

Key words: Intellectual disabilty, parents, practitioner, working relationship.

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User led services in Iceland: Challenges and future directions

The study introduced in this paper is based on my ongoing PhD research. The study addresses the current and future issues concerning welfare service for people with disabilities in Iceland. Its focus is on quality performance and organizational vision based on the philosophy of the model of independent living and the social model of disability. Research in Iceland show that professional supervision of traditional services by the ministry of social services is minimal leaving service providers to their own interpretations of directions, values and implementation and monitoring of services.

Services are mainly based upon the traditional, professionally driven services leaving individual control and empowerment to the minimum. A few individuals have through their own iniative aquired user led services. There is a great awakening among key stakeholders that the service mode rooted in the independent living principles would be more effective in ensuring fundamental rights, equality, full participation and individual control. May 1st 2009 has been set as the deadline for the inition of the first independent living movement in Iceland. The objectives that guide my research in this context are the following:1)To develop a proposal for practical criteria for guiding the implementation, self-evaluation and quality control of user led services within the context of the welfare system in Iceland. 2)To look at the challenges that the proposed quality indicators pose to the traditional services for people with disabilities. 3) To examine the value of using the criteria for the revisions and reorganization of the professional curriculum for social educators. The third and the last objective builds on the belief that the criteria recommended for measuring service quality could also serve as the framework for goal setting and curriculum development within the department of social education at University of Iceland. In this fashion, the curriculum could become one of the procedures to make values underlying service quality a reality. Social educators are key professionals in social services for people with disabilities in Iceland and therefore it is of utter importance that their professional theory develops in accordance with the sought after values of user led services. Data is collected in Iceland and the neighbouring countries by interviews,participant observation,written references and the method of best practices. The study adheres to qualitative research methods with grounded theory as a tradition of inquiry. In this paper the first results of my study will be introduced. Special emphasis will be on the meanings and expectations that people with disability and other major stakeholders attach to the concept of user led services in the light of their experience with traditional services. As well as to shed light on the current situation in Iceland in the light of this subject. Emhpasis will as well be on the key issues and challenges of the independent living movement in our neighbouring countries that could be of great value for the development and initation of user led services in Iceland.

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Participation in leissure time activities

In 2008 the National Board of Social Services carried out a survey concerning the participation in leisure time activities among people with disability. The aim of the survey was to examine to what extend people with disabilities are participating in ordinary leisure time activities. The survey follows up on a former survey conducted in 2003, and aims to examine changes in the degree of participation and qualitatively examine some of the organisations where changes has happened i.e. where they have recruited new members with disability. What have these organisations done and why have the new members chosen to join the organization and not a segregated activity? On the basis of the findings from the project, we intend to initiate new projects and communicate the new knowledge about how to include more people with disability in ordinary leisure time activities.

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Giving, taking, accommodating: Investigating different structures in interactions between children with disability and their parents

This paper presents results from an ongoing study. The study is part of research being done in relation to an early communication intervention program developed in Sweden called AKKTIV (Augmentative and Alternative Communication Early Intervention). The program consists of two parental courses (ComAlong, ComHome) for parents of communicatively disabled children. The main objectives of the study are to: (a) analyse the range of ways in which parents and their preschool children with disabilities may structure their interactions and (b) on the basis of the findings discuss implications for early communication intervention. In conducting micro-social analysis we focus on interactional structures and how they are constructed and achieved by the children and their parents. Three parent-child dyads are analyzed involving parents who participated in the "ComAlong"-parental course and their children. The children, aged between three and six, had communication difficulties of different types and degrees. The three excerpts show different methods for constructing order and sense in social interaction. They include a case with highly restraining parental management of the social interaction with a disabled child, a case where parental interactional contribution is supportive of the child's own initiatives, and a case where there is lack of parental involvement in developing the interaction. All interactions took place in the homes of the parents and children and the activities were chosen by the parents and children themselves.
By describing interactional patterns as a product of the dynamics of interaction we complement the usual clinical tendency where focus is put on the inherent characteristics of different disabilities and where communicative behavior is seen as generated by the disabilities. We argue that by focusing on the disability as a primordial cause of a child's behavior and participation in the social world, one will automatically be inclined to disregard the importance of the dynamics of the social interaction itself. For analytic purposes we therefore investigate interactional structures in interactions between children with different communicative disabilities and their parents The paper thus aims at illustrating how the method of micro-social analysis of social interaction may contribute to the evaluation of parental strategies for managing social interaction with their children and thus how the approach may contribute valuable insights to intervention teams.

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It is easy to live in Lund – for everybody

We live in a time with more possibilities than ever in all aspects of everyday life. At the same time, we feel a growing uncertainty in the face of all the responsibility we have to take and all the choices we have to make ourselves, and also because we always have to prove that we are good enough. Problems like lack of accessibility, participation and influence make life even more difficult for many people. However, right in the middle of the field between difficulties and possibilities there is a positive and urgent challenge: to promote and encourage people's driving forces to realize their dreams and personal life-projects. For everybody to be able to live a good life, encouragement and guidance are required which function in the spirit of the times and people's everyday lives. Everyone Benefits is a strategic resource with the Department of Culture and Leisure in the Municipality of Lund in Sweden. A set of tools has been collected for people working in various fields. Its purpose is to facilitate the work for participation and enable people with disabilities to have more influence over their lives. With the tools provided by Everyone Benefits it is also easier to discover what can be done and where it is possible to collaborate with other fields of activity. It is a comprehensive toolbox that works. The tools are:

1. The Active Meeting – it's the everyday impressions that make a difference
2. The Companion Card – pay for one, have fun together
3. Friend Support – a short cut to real friendship
4. Open to All – a guide to welcoming organizations
5. Impressions and Expressions – everybody should be able to exert influence

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Constructionist bottom-up analysis as a research strategy in order to identify professionals' self-perception as a condition of realising inclusive, educational strategies

Introduction: My study in inclusive, educational strategies is based on the part of the policy- and implementation research that focus on bottom-up-analysis. Bottom-up research criticises the top-down perspective that reduces the complexity of the policy process. Top-down research look at the formal parts of the policy process: the goals, leadership, organization, the structural level and so on. Instead the bottom-up research argue that policy processes – and in this case pedagogical processes – must be investigated by identifying the problems that are articulated and tried to be solved by the key agents in praxis. In this case the teachers. That put focus on the informal part of the process and a focus on the teachers' pedagogical praxis.

It is my starting point that the teachers' pedagogical praxis specially is based on their professional self-perception. Investigating the informal parts of the pedagogical processes and the pedagogical praxis therefore focus on identifying the teachers' professional self-concept as a central element of the conditions of realising inclusive educational strategies. Or, to put it in another way, the teachers' professional self-perception is an important part of the barriers and therefore also a part of the solutions according to realizing inclusive strategies in schools.

Purpose: In this abstract I will focus on:
1) Defining the concept of teachers' self-perception
2) Introducing the constructionist bottom-up method as a research strategy to identify teachers' self-perception.
1. The professional self-perception is defined as the discourse field of pedagogy. The teachers reproduce some underlying discourses in their construction of pedagogical discourses in praxis. Both the discourses produced in praxis and the reproducing of the underlying discourses, constitute the discourse field of pedagogy. By exposing the discourse field it's possible to identify the professional self-perception of the teachers. The main discourses of the pedagogical field can only be pointed out by investigating the teachers' pedagogical praxis.
2. The constructionist bottom-up method seems to be useful in order to produce knowledge about teachers' professional self-perception and in order to achieve a deeper and better comprehension of the logics and meanings dominating in the specific praxis. The teachers produce narratives about their teaching in praxis, and the narratives are analysed as documents in order to identify the main discourses in the pedagogical praxis. By identifying the main discourses in praxis we get knowledge about teachers constructing meaning, categories and identity in their profession and as professionals.

The further purpose of identifying the professional self-perception is to analyse which inclusion and exclusion processes, the teachers' way to construct pedagogy in praxis, lead to.

Conclusion: The teachers' pedagogical praxis is specially based on their professional self-perception. Identifying this concept makes it possible to investigate how teachers are constructing pedagogy in praxis and which inclusion and exclusion processes this leads to.
The constructionist bottom-up method and production of narratives as documents, is a productive way to identify teachers pedagogical praxis based on their self-perception.
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Professional social representations of children and parents with cognitive dysfunction

Objective/Purpose
This paper presents a recently initiated research project and some preliminary data aiming to highlight the professionals' perception of their work in families where parents have cognitive dysfunction.

Method
Focus group interviews will be used including professionals from social services, rehabilitation services, maternal and child health care, family centrals, preschool and school. Using this method it is expected to provide an increased knowledge of the professionals' perspectives about their work in the family and children's needs and conditions within the family. Using focus groups provides an opportunity for meaningful production where the participants in interaction with each other, share their different experiences and perspectives on the field. Participants are given the opportunity to share their experiences and examine different ideas, values and ideas with each other. Issues that will be focused are what professionals perceive and describe as important input for children with cognitive dysfunction living with parents who have similar dysfunction. How do the professionals reflect on the needs and on their own contribution in these families?

Results and Conclusion
The results will present the structure of this research project as well as some results from the focus groups. As a theoretical framework, social representations will be used to capture the change that occurs in the groups.

Key words: Professionals, social representations, cognitive dysfunction

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Baba Amte's Anandwan Leprosy Project shows world making potential

Does leprosy still exists? People with leprosy are primarily, victims of the most terrible scourge possible? How does leprosy evolve into a world? How does it relate to a larger world ?

Justification for study: Still there are around half a million people in India with leprosy, some active and many dormant. Since a considerable number of people are living with the social consequences of the disease, an ethnographic study of people affected by the disease would, of itself, seem justified. Given the paucity of published material dealing with the social implications of leprosy in a qualitative way there is room for research studies on leprosy in different parts of India. Critical enquiry within the confines of a particular leprosy community serves to challenge, wider assumptions of the body, community-making and social identities, while extending theoretical debate on power, resistance and Indian ways of knowing and being-in-the world.

India has over 600 rehabilitation sites for leprosy affected people. Such leprosy centres are associated with guys who look different: people without eyebrows, thickened ears, collapsed noses, clawed fingers or no fingers, less or no toes, without arms and some with no legs. These are guys with deformities but have no leprosy. They have been cured but those who have lost parts of their bodies cannot grow them back. Many such people have been acting as my informants in the field in the last three years.

Leprosy, as a disease never physically kills its victims, but when untreated, keeps producing distinctive deformities. It has played a unique role in creating a category of the socially excluded that is distinct from the other forms of "untouchability" in Indian society. In Anandwan where I do my field studies, leprosy is the unifying factor. The inhabitants of Anandwan are carving out a fresh identity for themselves as "lepers of a different kind". They like to be referred to as "person" affected by leprosy" or "leprosy-affected people" and not 'leper' or leprosy patient? Leprosy patient can imply a lack of agency and could suggest some form of ongoing medical care even when the guy has stopped treatment decades ago.

From my informants I learnt that many do not like to go back after they are cured. They learn new trades, find jobs in and around Anandwan, bring their ageing parents to stay with them. Many of the older folk when they are helpless are ready to come and live at Anandwan. Some also bring the children of their brothers or sisters or relations to come and stay with them and pursue studies in the schools, colleges or work as apprentices in the various workshops or in the man power training centers they have erected with their own hands. In the open society they do experience ostracism but not in Anandwan because the past of the majority is tied with leprosy.

In the history of Anandwan Mahatma Gandhi has a special place. Gandhi has certainly had an impact on the thinking and praxis of Baba Amte and his colleagues in the setting up of Anandwan for leprosy affected people. This is how Mahatma Gandhi looked at the idea of anyone wanting to do social work. He said, "I shall give you a talisman. When faced with a dilemma as to what your next step should be, remember the most wretched and vulnerable human being you ever saw. The step you contemplate should… !

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The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs - European Study

The paper will introduce results of European study where the Specific Risks of Discrimination against Persons in Situation of Major Dependence or with Complex Needs were analyzed. The comparative study was conducted in 12 European countries: Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United KingdomLife course approach was used as a method. Results of the study indicates that people with severe disabilities face typical and specific risks of discrimination in all European countries and in all areas of life, but to a different extend. It is small and diverse group that creates no interesting market for goods and services, and therefore product innovation is often restricted.

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Employment and disability in Norway and Denmark

Most of this century employment in general has been high in both Norway and Denmark, but research shows that the employment of people with disabilities has increased in Denmark, whereas it has not done the same in Norway. Perhaps it has even decreased a little there.

On the basis of recent population surveys we shall examine the participation of people with disabilities in the working life in detail: type of jobs, role of education etc. Can we through such a detailed description reach at an explanation of the different development in employment for people with disabilities in the two countries?

Furthermore, we shall find out what is the effect of labour market participation on the standard of living of people with disabilities. In that connection we shall compare standard of living indicators such as income, housing, family, and inclusion in social networks. We shall also compare indicators of quality of life, and ask the question of the relation between poverty and disability. How much is disability the background for poverty, and how much is poverty the background for disability?

The most interesting question is, however, how far we can get in "explaining" the possible effects of labour market participation on standard of living for people with disabilities. Are we satisfied with explaining in terms of individual characteristics (such as type and degree of disability, time of acquiring disability, gender, age, education etc.), or should we also include the effects of welfare state support and participation in working life?

The research builds on surveys conducted in Norway and Denmark in 2006. Both of the surveys are based on great random samples of the population in working age, resulting in 7-8000 completed interviews in each of the countries. It is also the intention to compare with similar surveys in the United States. This will give the idea of the consequences of a welfare system that is very different from the Scandinavian one.

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Building Bridges?

Abstract:
Aim: To examine how research could build a bridge between social care and people with learning difficulties. Methods: During 14 years I have used a co-research paradigm in which six persons with learning difficulties work with me to develop focal questions, gather, interpret and present the data. The working process give them possibilities to learn about society - and let the society learn by them. On their behalf, I will present the results of our observations, interviews and first-hand experience concerning the implementation of empowerment philosophy in Swedish programs for people with intellectual disabilities.
Results: The results showed for example that these people have interesting research-questions about their every-day-of-life experiences. They for example teach students about their attitudes and they as people with learning difficulties learn about society they shall be a part of. The research-method also empowered them to get a better self-asteem. This research-method also shows that those who are professional social care-worker some-times help them improve their life conditions. But sometimes these factors that should support and empower people with learning difficulties are misused. These factors will be exposed. Conclusion: To build a bridge between research and social care is possible to do. But this kind of intervention is also a subject to misuse. Distinguishing high fidelity efforts to empower people with learning difficulties from those without real commitment to this philosophy requires attention to staff intention, action, outcomes and follow through over time. This kind of research takes a lot of time but can be done by themselves as people with learning difficulties together with research-support. And they grew as a person.

Theme & Topic: Empowerment,; Participatory Action Research; learning difficulties, a pedagogical approach; social care.

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Home & Away: the impact of educational policies on young disabled people's experiences of family and friendship

In the past 60 years there have been considerable developments in the policy and politics of schooling for disabled children, including a shift of rhetorical emphasis from more segregated to more inclusive approaches. Previous research with disabled children in the UK has raised questions about the educational and social impact of segregated educational provision and about the role of special schools in an inclusive society. Specific concerns have also been raised about the social implications of policies and institutions that require some disabled children to live away from their families. Yet analysis of disabled people's own accounts of special schooling has focused primarily on the educational experience rather than on the implications for family life and friendships. This paper combines critical policy analysis with examples of qualitative life history data to examine how segregated educational provision has affected disabled children's family lives and relationships since the 1940s. In this way, it also demonstrates the potential for connecting public and private accounts of disability by linking macro and micro levels of analysis over time.

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The role of family in the aspirations of young disabled people

Family is one of the most influential social structures in society, moulding children and impressing them with certain expectations, values and beliefs which shape their educational aspirations and career choices throughout their life course. This paper explores the role of the family in shaping the career choices of young disabled people. It reviews the literature to identify which specific family characteristics influence the development of aspirations. It focuses particularly on how family encourages and hinders the pursuit of certain career routes through expectations, support and advice. Disabled young people may not be socialised in the same way as their non-disabled peers or siblings due to the influence of medical model thinking, where the impairment is perceived as the problem. This has left many families unsure of what to expect of disabled children, thus excluding them from many important patterns of socialisation and social processes. This paper presents empirical data from a three year study with young disabled people, giving accounts of their relationships with parents and siblings, and how family structures shaped their aspirations and choices, for education and employment. Themes include parental expectations, socioeconomic background, parental occupations, and same-sex role modelling and the development of gender typical aspirations. By listening to the views of young disabled people, families and government can learn how they can contribute to the full citizenship of young disabled people and their inclusion in mainstream society.

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Let's talk about disability: But who and how?

Objective/Purpose: In the context of the ongoing debate whether Disability Research gives appropriate answers to questions and problems imposed from society on persons with disabilities, Austria provides a good example for discussion. Here, disability still is a kind of a socio-political non-issue. Nearly no public debate exists with regard to disability. Also and due to the existing barriers, persons with disabilities are still more or less invisible in everyday life. Only once a year disability becomes a publicly discussed issue when the charity campaign 'Light into the dark' reaches ist peak around Christmas time. To raise money for families with children with disabilities, the pictures shown and the words used during this campaign aim at generating pity, compassion and sympathy. Hence, in Austria one way to 'deal with' persons with disabilities is not to talk about them. Another way to talk about disability in Austria is to argue that everything is okay and that Austria has already initiated a paradigm shift with regard to disability politics. The not yet published 'Report of the Federal Government on the status of persons with disabilities in Austria 2008' (Ministry for Social Affairs) argues in the context of the discussion of the UN convention on the rights of persons with disabilities that it can be assumed that Austria has already fulfilled the legal requirements. Besides this non-discussion of disability related socio-political questions and this non-reflexive way of governing disability in Austria, disability can also be paraphrased as a scientific non-issue. While a dispersed group of researchers tries to establish Disability Studies and Research within the Austrian academic context, some representatives of Austrian universities reject Disability Studies as a scientific field, saying that Disability Studies scholars mistake scientific activity for a platform of agitation of interest groups. Also, the argument goes, the concept of disability is based upon a utopian concept that does not reflect lived experiences of persons with disabilities. It is the aim of the presentation to discuss challenges for Disability Studies and Research by discussing the Austrian example and the debates around the process of establishing DISTA (Disability Studies Austria).

Method: (a) interviews with disability rights activists and policymakers, (b) participation/participant observation and informal interviews (at several sites), (c) document, media and literature analysis

Results/Conclusion: The situation in Austria provides a good example to discuss divergent ways of talking about disability and shows the importance of researching disability. Critical observers of Disability Studies in Austria argue that it is important to analyse questions such as inclusive education, labour force participation rate of persons with disabilities, assistance or a new understanding of the body, not informed by consumerism – with a direct reference to living with a disability in Austria. In order to bridge the gap between science and lived experience of persons with disabilities, it is necessary that Disability Studies and Research tries to give answers to practical socio-political problems. In addition, the Austrian example highlights the importance of Disability Studies and Research in the context of transforming disability from a socio-political non-issue to a relevant issue.

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Evidence-based participatory disability research

Objective/Purpose: In an era of evidence-based policy and practice it is necessary to reflect upon what the concept of 'evidence' means for applied health and social research with people with disabilities. Policymakers emphasise the need for scientifically 'tested' interventions and best practices. Claims are frequently made that 'evidence' exists to justify policy. For example, 'self care' has become a focus for long-term health and social care policies in the United Kingdom based on allegedly solid research evidence. Upon closer inspection of the research underpinning 'self care' methodological shortcomings become visible. Similarly, health-related interventions may be offered to people with disabilities without having been tested for safety or effectiveness. Even more importantly, health-related research priority and agenda setting often takes place without including people with disabilities in the process. In this presentation, we will discuss how the claim of having scientific evidence is used to underpin resource allocation policies and intervention practices and how its nature and quality is understood from the vantage point of different key stakeholders.

Method: Using a structured literature review focused on health-related intervention and public health research, we will critically examine methodologies and explore the extent to which people with disabilities have been excluded from applied health and social research, including population-level surveys and clinical research. The literature review was limited to five major databases MEDLINE, CINAHL, PSYCINFO, EMBASE and COCHRANE SYSTEMATIC REVIEWS DATABASE and the years 2000-2007.

Results: Few research publications indicate whether specific accommodations were made for people with disabilities to participate in a research project. Exclusion criteria did not specifically rule out participation of people with disabilities but sampling, consenting and study administration procedures in effect did. Non availability of alternative formats to obtain consent or allow active study participation, reliance on proxy respondents, insufficient interviewer training, exclusive reliance on single methods, and stringent clinical trial inclusion criteria are issues that increase the likelihood of research non- participation. There are many implications of non-inclusion. For example, there is no guarantee that health interventions are effective or bear additional risks. Moreover, most health-related research fails at finding meaningful ways of involving service users in identifying key research priorities, formulating research questions, and shaping an inclusive research process. This also requires consideration of other sources of 'knowing' outwith the scientific domain. Experiential, practical and scientific knowledge need to be integrated. Participation is not only essential as part of scientific knowledge generation but also in terms of its translation into sensible action programmes. People with disabilities are frequently denied opportunities of expressing their priorities, preferences and requirements in how health and social interventions ought to be implemented.

Conclusions: Non-participation of people with disabilities in research is a social justice issue in two ways. Firstly, it deprives people with disabilities from opportunities of shaping meaningful research agendas. Secondly, it leaves health interventions untested und non-validated and potentially increases the risk of harm. A set of key recommendations to further enhance participation of individuals with disabilities in applied health research will be made.
Key words: Evidence-based practice; participatory research; methodology; exclusion

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MEDIA, DISABILITY AND EMPLOYMENT: MAKING THE DIFERENCE

This presentation aims to reflect how society understanding of disability has a direct effect on people with disabilities' human rights and it will also try to reflect how the media can make the difference, by mainstreaming disability and employing people with disabilities.

The presentation includes an introduction that explains the cultural and social background of the current situation reflecting how the division of people into categories can create two identities; the real one and the virtual (the one society imputes as being part of a predefined category) and how categorizing people create stigma when they provoke a negative perception on the people.

This lack of human rights will be connected with the CRPD and the Media perspective, analysing those human rights should be respected and how the media can make the difference from its double perspective; provider in terms of goods and services and as a potential employer of people with disabilities

It will give different tools and good practice experiences, based on a cooperation approach between media and Disabled People Organisations (DPOs), in order to demonstrate that making the difference is possible:
♣ Increasing and improving the portrayal of people with disabilities in the Media Project: which includes a disability guide (developed by Broadcasting and Creative Industries Disability Network) which provides interesting information about employing people with disabilities in the media. It also includes some interesting conclusions by the Media and DPOs at the end of this project conference
♣ Spain: Actions taken by Fundación ONCE as part of the project mentioned above and future perspectives; also some other good practice

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Deinstitutionalisation and after – the current state in Norway

The 1990s were years with important reforms for people with intellectual disabilities in Norway. All residential institutions were closed and people resettled in group homes or semi-independent living in the community. State run special schools were also dismantled, thereby finalizing a development starting some decades ago. Local authorities became responsible for both primary education and residential services for people with intellectual disabilities.
This presentation will sum up the experiences during the reform period and also address the developments after the media attention faded. Regarding adults with intellectual disabilities, the presentation will address changes in housing/living arrangements, employment, social contact, leisure activities and self-determination before, after and ten years after the closure of institutions. The state of affairs will also be related to the reform intentions and ideals. The more recent developments of large group homes, larger than most new institutions in the 1980s, will be scrutinised. Regarding children, current trends in school placement and educational arrangements will be presented and discussed in relation to the ideals of inclusive education. It is asked whether the progressive nature of Norwegian policies and practice of the 1990s in the field of intellectual disabilities has withered.

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Jesper Holst, Aarhus University, School of Education

Deinstitutionalisation of every day living conditions of persons with intellectual disability – the current state of affairs in Denmark

Starting from the decentralization processes in the 1980ties, during which the responsibility for provision of service and residential accommodations for persons with intellectual disabilities was transferred from the state to the counties and during which visions coded with terms like normalization, integration, co-determination and community living became decisive for the moving out of the central care institutions, the presentation will relate to the recent development of the deinstitutionalisation process. Thus, focus will be on the Service act of 1998 with its formal abolishing of the concept of institution and on the new guiding visions such as self-determination, participation and quality of life. In January 2007 the municipality reform came into force with the consequence that service and establishment of residential accommodations for persons with disabilities became further decentralized as the responsibility was transferred from the counties to the extended municipalities established by the reform. Some of the current discussions concerning the consequences and the issues this reform brought along will be presented.

The state of affairs concerning the deinstitutionalisation process will be carried through at 3 levels. Firstly, the framework of the relevant laws and the implementation of the laws will be examined. This comprise a discussion about discrimination in relation to the differences which emerge by the situation that residential accommodations can be established and managed both under the Service act and under the Public housing act. Secondly, the placement and the architectonic design of the residential accommodations will be examined which among other things include the dilemma between the wish of many municipalities to establish financial and professional justifiable residential accommodations and the wish of different pressure groups to ensure that persons with disabilities have access and possibility, like other citizen, to choose between a range of different types of dwellings. Thirdly and last, the focus will be on the every day life in the residential accommodations as the degree of institutionalisation also is related to the attitudes, ethics and professional approaches involved in the being together and the communication between residents and professionals. This will also comprise the contrasting demands to the professional support staff for instance on one hand to meet the residents as fellow citizen and on the other hand to prove professionalism and worth by treating the residents as life long development projects.

Rannveig Traustadóttir, University of Iceland

Trapped in the Institution

Despite ideologies and policies to the contrary, we continue to segregate disabled children and adults. Despite 30 years of deinstitutionalization we still seem to be trapped in the institution, if not in segregated buildings then in practices that extend beyond the institutional walls. Like in other Nordic countries, the ideology of normalization and integration had a great deal of influence in Iceland and brought new policies and new forms of services for disabled people. This presentation will review the history and process of deinstitutionalization in Iceland and the current state of affairs with regard to the inclusion of disabled people in everyday community life, with a particular emphasis on children, youth and adults with intellectual disability. I will attempt to answer questions such as: Has deinstitutionalization brought a straightforward change in services from institutions to community-based services, or a more fundamental shift in the way people with intellectual are understood and constructed? What are the current emerging themes in deinstitutionalization and community life and to what extent have we re-created institutional practices in community services? Why has the full inclusion of disabled people in everyday life been so difficult to realize? Now that many view normalization and integration as outdated, what ideologies guide policies and practices in disability services? The presentation will, in part, be based on several Icelandic research projects, most of which have sought the perspectives of disabled people themselves. Some have examined the lives of disabled children and their participation in schools and various aspects of everyday life. Others are life history studies with adults with intellectual disabilities which have taken a historical look at their experiences of deinstitutionalization as well as studies exploring the social and cultural participation of young adults with intellectual disabilities.

Antti Teittinen & Hannu T. Vesala, Finnish Association on Intellectual and Developmental Disabilities (FAIDD)

Deinstitutionalisation in Finland

The aim of this study is to describe the development of services for people with intellectual disability (ID) in Finland during the last 50 years focusing on the deinstitutionalization. During the last five decades the changes occurred in the field of ID have been so drastic that we can even speak of them as paradigm changes. These changes have concerned to the people with ID, the services offered to them and the people working in services as well as to the whole service-system and these changes have reflected the changes happened in the whole Western society. The most apparent changes in the services have been movement from large segregated institutions to smaller, community-based services, change from special services to generic services and emphasizing the customer orientation and individuality in the provision of services. In Finland, the deinstitutionalization has happened quite late compared to other Western countries. The number of people with ID living institutions declined 50 % during 1990's, but with one exception, institutions have not been totally closed until 2000's.

These changes have at least partly been driven by ideologies adopted in the field of ID. The normalization principle emphasized the rights of people with ID to live in the same way as all the other people, and integrating them to the community and society was seen as a central vehicle to achieve normalization. Later, integration was replaced by inclusion, which put the emphasis on changing the environment and the society open and accessible for all people, instead of aiming to change the individual to fit in the society.

On the other hand, the development in the field of ID has also reflected the changes in whole society. At the societal level ideological changes towards neo-liberal ethos i.e. New Public Management (NPM) have emphasized the demolition of bureaucratic governmental structures because of economical reasons. In a cutting process of social services it has been focused on the service users' own rights, risks and responsibilities in the name of inclusion. This phenomenon has concerned people with ID too. Also usual consequences of NPM are changing characteristics of caring work like multi-professionalism, needed new qualifications, temporary employments and gendered work. At the same time better housing conditions of moving persons are argued by inclusion to aim a full citizenship, human rights and responsibilities. As a conclusion there is a paradigm shift in housing practices, but it includes two opposite ideologies. Parallel processes are interpreted in the frame of the Giddensian structuration theory.

Magnus Tideman, Halmstad University

Decentralisation, variation and categorization – The current state in Sweden

The responsibility for support, services and education for people with intellectual disability was decentralised to the local authorities in the beginning of the 1990ths. During the main part of the last 20 years the development in Sweden was dominated by economic problems.
The new disability legislation 1994, evaluates to have neutralized the deteriorations that the economic /financial problems of society could have brought for the living conditions of people with intellectual disabilities. At the same time the development was denoted by a change from a passably /rather equivalent national situation for people with intellectual disabilities to a greater variation at the local level.

Factors such as organization, economy and political government at the local level, together with an increased stress on the capacity of the individuals to look after their own interests, have resulted in the growth of differences in living situation and living conditions. The local authorities finished the deinstitutionalisation in the beginning of 2002. In addition to that, an increasing political interest of private entrepreneurship in the field of disability and a rise of categorization of children and youth as intellectual disabled has occurred. Categorization has first been noticed in special programmes at school but recently also in daily activities for people of a working age. The rise of categorization can be linked to a change to medical and individualistic based explanation of disability, which has opened up for growth of segregated activities. Examples of resistance against categorization and segregation among young people with intellectual disabilities are noticed. Empowerment by self-organized groups is a new trend.

In conclusion, the development in Sweden can be described as small steps towards normalization as a consequence of deinstitutionalisation along with a greater variation of living conditions due to decentralisation. At the same time an increased categorization has markedly expanded the group which counts as intellectual disabled.

Rannveig Traustadóttir, Center for Disability Studies University of Iceland

Disabled People and Nordic Disability Research

Internationally scholars from many fields have been creating disability studies as a new way of studying disability. In most countries disabled people have been in leading roles in establishing and developing disability studies as a new academic discipline. In the Nordic countries, however, this has not been the case. Instead, it has largely been non-disabled people who have developed this new field of study. This presentation explores possible reasons why disabled people have not been active in the creation of disability studies and disability research in the Nordic countries. It also examines the development of Nordic disability research in an international context and discusses the similarities and differences between Nordic, UK and US disability studies. A particular emphasis will be on exploring how disability studies in these countries define and locate themselves as new academic disciplines and how they relate to disabled people and their movements.

Peter Anderberg, Certec, University of Lund

The power of knowledge and knowledge of the power

In society today disabled persons encounter environmental, institutional, and attitudinal barriers on almost all levels and almost daily. Society has begun a path towards the full citizenship for disabled persons but there is still a long way ahead of us. One of the most important ways to follow towards this goal is participating in the knowledge creation and production in areas that directly concerns disabled persons. To influence this knowledge production is important both inwards to the own group and outwards to society. It has implications both for the creation of identity in a society, and also directly for the day to day politics. In the Nordic countries there are comparatively few researchers with firsthand knowledge of living with a disability. What are the negative implications for the Nordic disability research and for the disabled people's movement in the Nordic countries as a result of this? In this presentation the importance of more disabled persons as researchers are discussed and research on disability is analyzed against the background of Independent Living theories and philosophy.

Borgunn Ytterhus, NTNU – Norway

What kind of research does Nordic researcher publish – and is our research user-friendly?

It is an ongoing discussion in the disability research communities if disability research contributes to new knowledge additionally to ordinary social and humanistic sciences. It is also an ongoing discussion and almost a claim from different interest groups of disabled people to become involved in research and/or if disabled researchers in the research area contributes with other knowledge than non-disabled researchers do. These discussions correspond to some degree with political discussions and legislation of antidiscrimination and usability. In this field there is a mixture of concepts like user-friendly, user involvement, user relevance, user direction and usability. These concepts can be understood as concepts within two contradictory ideological and theoretical paradigm; respectively radical critical theory and new liberalism. This presentation is based on a review of publications done by Nordic researchers in the last five volumes of Scandinavian Journal of Disability Research (SJDR) and Disability & Society (D & S) during 2005 – 2008. Totally 38 articles are involved from SJDR, and 13 from D & S from all the five Nordic countries. The articles have been reviewed according to topic, research methods and what kind of knowledge they produce. The discussion tries to elaborate challenges and possibilities in the relationship between research as a professional phenomenon in interaction with its historical and social context. There seem to be mixed signals in the existing research whether Nordic research are moving towards a stand-point-epistemology of disability or not.

Pekka Tuominen, Nordic Federation for Associations of Disabled People (NHF) and European Disability Forum (EDF)

Why Should Disabled People be Interested in Disability Research?

My contribution to this symposium will be in the form of commenting on the issues raised by the other speakers, rather than giving a formal lecture. I will address some of the important questions raised by the other presentations such as: Is disability research useful or important for disabled people and their movements? Is the disabled people's movement interested in research? Does the disabled people's movement use disability research and how? What should be the role of disabled people in disability research and in developing disability studies? Why would it be important to have disabled researchers in disability studies/research? What are the current connections between the disabled people's movement and disability research? Why have disabled people in the Nordic countries not been active in developing in developing disability studies? In addressing these and other issues raised in this symposium I draw upon my experiences within the disabled people's movement in my own country, Finland, as the current Chair of the Nordic Federation for Associations of Disabled People (NHF) and as a member of the European Disability Forum (EDF).

Mette Sommer, Institute of sociology, Copenhagen

The deaf Diaspora; culture and mobility

Keywords: Reception analysis, Deaf people, Diaspora, network capital, cultural capital

Objective/Purpose: This paper discusses the movements of deaf people as a parallel to the concept of Diaspora communities. Diaspora communities refer to people living far away from their original homeland in a host country into which they are not assimilated. To view deaf people as a deaf Diaspora is born out of the fact that only 3 % of deaf people are born into deaf families (both parents deaf) where sign language, deaf culture, together with the unique understandings of life and needs of deaf people are a natural part of the family life. Most of deaf children are born "dispersed" without connection to other deaf people until later in life. Such connections are often formed when attending deaf schools or deaf clubs and these schools or clubs are often referred to as a second home. So there are some useful perspectives from the other diaspora communities in the discussion of e.g. the young deaf people's feeling of belonging to another place than their "host countries".

Because the concept of Diaspora communities also represents a context of mobilization, this paper explores the extent to which deaf people are mobilized within their current contexts and communities.

Method: The empirical data collection consists of reception analysis of Deaf tv-programmes produced by Deaf Tv and Døvefilm Video. Here I will focus on this program about the world's only Deaf University, Gallaudet. Gallaudet represents a deaf community in which a deaf person can constitute and confirm his/her deaf identity. The program follows three young Danish deaf persons who study abroad for one year.

Results and conclusion: Although all of the focus group participants were deaf and attended deaf schools, their reception of the two tv-programmes were highly differentiated by their deaf "cultural capital" in the sense that some participants have deaf parents or siblings and experiences in the international deaf community, whereas others don't. Moreover the participants differ in their educational attainment; some only hold the deaf school education (10th grade), whereas others have attended highschool and university. The findings in this paper suggests that educational attainment impacts deaf peoples possibilities of mobility within the deaf community, understood as different 'network capital' (John Urry).

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Disability and future ageing

This presentation is based on an ongoing PhD-project; Disability and future ageing The present time produce in some ways an assumption that we all have opportunity to create ourselves; who we seen as today and who we will be seen as in the future. It leads to the idea that we can plan the future and by that our ageing, and not least the media often reflects the image that it is possible to postpone ageing (and/or ease its consequences) by taking a series of measures in the present (e.g. physical exercise, proper diet or retirement savings). But is it always so easy? Planning is based on the idea of a planning horizon as if it is possible to predict the future, this future that is highly dependent on events at both personal and societal level. Planning for the ageing is also based on an assumption that there are resources to relocate for the future. The project's aim is to study disability in relation to the planned ageing. Do men and women with disabilities plan their future ageing? How? How do they formulate their contingent future needs? In what way interact such as economy, housing, class, gender, and ethnicity for the conditions that women and men with disabilities relate to? How are disability and old age expressed in the laws and regulations governing the welfare state efforts for people with disabilities and the elderly population? The study will be based on qualitative interviews with middle-aged people with disabilities, divided in broad categories; people with intellectual disabilities and people with physical disabilities. The purpose of study two groups is to catch the heterogeneous, not to compare people. The data collection will be divided into two phases; the first part will be consisting of narratives where the informants talk relative freely about their lives and their own experiences. It increases the prospects of reaching an insider's perspective and by listening to how people give their lives meaning and creates their identity, and hopefully will give a better understanding of what the experience means to the possibilities of life planning. The second phase will be a follow-up interview that focuses on thoughts off future age, strategies for the ageing, and other issues that have emerged in the analysis of the first interview. The theoretical framework is built up on social constructionism, social categorisation and analyzes will be made from an intersectional perspective.

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Disability theatre in a Nordic context

Nordic disability theatre is a relatively new and interesting field of disability research. In this paper presentation we give an overview from the field of disability theatre in a Nordic context. The paper is based on a comparative analysis from three research projects conducted in Sweden and Norway. The projects were using qualitative methods and was analysed from different theoretical perspectives. Interviews and participatory observations were conducted at four different disability theaters involving actors with hearing impairments, intellectual disabilities, physical disabilities and mental disabilities. The aim with the paper presentation is to illustrate how the organisational settings reflect diffrent goals and aims at the political and artistic level. We are also discussing the relationship between the theatres, the public opinion and media. Finally the paper illustrates in what way organisation, recognition and the public approval play an important role for the actor's identity formation and sense of belonging.

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Pregnancy and birth outcomes in women with intellectual disability in Sweden: A national register study

Objective To describe pregnancy, childbirth and newborn health in Swedish women with intellectual disability and their infants Design A population based study using data from the Swedish Medical Birth Register Setting Sweden 1973-2006 Population Women, (n=2310) with the diagnosis F70-F79 retardatio mentalis who gave birth between 1973-2006 Methods Women were identified in the National Patient Register. Their personal identification number was linked to the Swedish Medical Birth Register, which resulted in information of 2310 births Main outcome measure Pregnancy complications, mode of delivery, stillbirths, birthweight, neonatal death Results One-third of the women smoked at pregnancy week 30-32 and epilepsy was almost four-fold over-represented compared to the general Swedish population. The women used less pain relief in delivery than women in general. The children were born preterm in one-fifth and had a low birthweight in ten percent. Conclusion Improved quality of prepartum and intrapartum care is required for women with intellectual disability, for example more and extended antenatal health visits with enhanced parental education as well as better interpretion of and response to labour pain.

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Normalization, authenticity and reflexivity – on staging ordinary life in disability care

This presentation attempts to elaborate on the scholarly discourse about normalization in disability care.

The aim is to discuss the tension between artificially created, authentic reality in activities that try to achieve normalization for people with disabilities. The discussion is carried out by using examples from theatres for people with intellectual disabilities and home care for people with long-term mental illness.

One point in the presentation is that both theatres and home care involves institutional ambiguities. When welfare institutions attempt to imitate authentic everyday life, the assumption is that this would bring about positive effects for clients. I argue that it is difficult to create this kind of authenticity within the therapeutic context of disability care.

Using Giddens conception of late modernity, I argue that the problem of imitation is less problematic. The design of normal-appearing environments in disability care seems to be similar to and no less artificial than what is the case with normal people, in an age where individuals increasingly tend to reflexively create their identities.

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Shame, apathy and souls of fire

Shame, apathy and souls of fire Abstract One aim of the Swedish disability reform from 1993 is to guarantee that it shall not matter where you live. But still there is substantial local variation indicating a problem of spatial inequity. This case study further explores that problem. It is true that the volume of support (number of persons and support measures as well as costs) under the Swedish disability act (commonly called LSS) is a result of collective action. But individual persons, such as politicians and civil servants make the decisions. The aim of the study is to analyse the implementation of the reform in a specific region. Focus is on political ambition. Can knowledge of the attitudes that different political actors hold towards LSS contribute to an understanding of the implementation? Politicians, civil servants and representatives of disability organizations in three different types of municipalities were interviewed about attitudes towards the reform and their disability policy. One main difference between the municipalities was the volume of support under the Swedish disability act. Three alternatives of actions were discussed. They are active and passive abidance by the law and behaviour contrary to the law. The alternatives can be related to three actor roles concerning actual behaviour. Results showed that different actors within and between the municipalities used different alternatives of action. Their actions corresponded to different attitudes towards their own behaviour: shame, apathy and a soul-of-fire attitude. Three requisites are necessary for political reforms to come into effect. Political actors must understand what the reform is about, what problems the reform is meant to solve and what goals are meant to be reached. The actors must have the will to implement the reform and also the ability, which usually means economic resources. The actual alternatives of action and the attitudes were related to these implementation requisites. The results show that the different political actors understood the political intention with LSS. They also maintained that enough economic resources had been allocated to meet the needs for LSS-support. However, the will or ambition varied leading to either an active or a passive mode of action, even behaviour contrary to the law. Not surprisingly, passivity corresponded with "shame" (for doing so little) or "apathy", whereas activity correlated to a "soul-of-fire attitude". Policy implications were discussed. More money from the State will probably not improve the situation as nobody complained about lack of financial resources. Maybe shame can be a motor to further development of the disability care so that a disabled person can get the support where he or she lives and not has to move to another municipality? Or is legislation needed to strengthen the individual freedom of choice?

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Gudrún V. Stefánsdóttir, University of Iceland

What is the "true" story?

This presentation is based on inclusive life history research with people with intellectual disabilities where some of the participants were co-researchers. The study raised question about how the memory works and influences the views and perspectives of the story tellers with intellectual disabilities, and what is the "true" story of people's lives.

Berit Berg, Associate Professorand Torunn Fladstad, Researcher, NTNU Social Research, 7491 Trondheim, Norway.

Migrant families with disabled children and the service system

Research on families with disabled children tends to show that they have a problematic and frustrating relationship to the service system. Within this research area, non-western migrant families are often underrepresented or non existent. The aims of this project are twofold: 1. To gather more knowledge about the challenges met by migrant families with disabled children. 2. To develop strategies for improving collaboration between the service system and the families.

This ongoing study is being carried out in three regions in Norway: Oslo, Trondheim and Kristiansand. It is based on qualitative interviews with families and professionals, observation of children in day care and at school, and participation in meeting with parents and professionals. The majority of the parents are first generation migrants from different countries: Sri Lanka, Pakistan, Somalia, Iraq, Iran, Vietnam, Lebanon... The participants are interviewed about such issues as information, language, communication, culture, ethnic background, education, economy, time spent in Norway, refugee background, understanding of disability, treatment and potential for learning, expectations to and experiences with the service system, the transitional stage between day care and school, social network and family support. More general issues are also discussed related to the families' minority status, and discussions about integration or segregation in our society. The project focuses on the variation in experiences of collaboration with the service system and general life situation, from the perspectives both of minority group membership and of having a disabled child.

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Minority ethnic families with disabled children – a review of the literature

Research on families with disabled children describes how these families face many challenges in their daily lives; lack of information, practical and emotional stress, and struggles with the service system. Families with minority ethnic background are for various reasons seldom included in such studies, and there are few separate studies about minority ethnic families with disabled children. Thus we have little knowledge about such families. How do they understand disability? Do they face the same challenges as families with disabled children from the majority population? Do they have other or additional problems because of their status as ethnic minorities?

This paper presents a review of the literature in this field in order to try to shed light on the above questions. The literature is roughly sorted in three areas: family attitudes towards disability, encounters with the service system and experiences of children and youth about living with a disability when one is a member of a minority ethnic family.

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Rannveig Traustadóttir, Professor and Director, Centre for Disability Studies, Faculty of Human and Social Sciences, University of Iceland.

Disability and Ethnicity: Using intersectionality to understand complex lives

In recent years there has been an unprecedented upsurge of interest in the areas of disability and ethnicity. Both raise a number of important theoretical and empirical questions at an individual as well as a structural level. Both disability and ethnicity are common personal experiences and global phenomena with widespread economic, cultural and political implications for society as a whole. Most often disability and ethnicity have been explored as separate issues despite the fact that they are always intertwined in various ways. When disability is combined with ethnic minority status it often creates complexities in people's lives which are exacerbated by the intersection of other social aspects such as gender, religion and social class, and the fact that both "ethnic minorities" and "disabled people" are highly diverse groups. This presentation discusses ways to examine the intersection of these multiple dimensions of difference. It is an exciting area of inquiry and crucially important as many of the categories create multiple layers of discrimination and social exclusion. Theories of intersectionality are proposed as a fruitful way of exploring and understanding this complexity. The discussion also draws on a small study of immigrant families with disabled children in Iceland.

Søren Langager, Associate Professor, Danish School of Education, Department of Education, Research Programme in Social Pedagogy and Special Education, University of Aarhus.

Inclusion Paradoxes
- Alterations in the conception of normality, normalization policy and the privileges of diagnosis

The ideology of inclusive pedagogy and education is challenged by societal changes that appear to confront the traditional conception of the differences between normal and abnormal. A transition from 'either-or' to 'more or less' categories resulting in a changed view on diagnosis and consequences for those who get one, followed by a considerable self-normalization policy focussing on individuals themselves to take responsibility to behave and act normally in the 'right way'.

The presentation emphasizes inclusion and exclusion tendencies in society and in professional 'good practice', and increases the key issues to a more overall perspective based on topics such as diagnosis and neuroscience, normalization and governmentality policy, differentiation and inclusion ambiguity.

Altogether, there is a picture of tendencies, that tends to overrule common professional special education and social pedagogical conceptions of normality (them and us, the normal and abnormal, the included and the excluded), and questions whether the inclusive pedagogy in practice follows other paths than those, that colloquially is in play within the educational and pedagogical institutions' self-perception. A development followed by a new differentiation with the 'privileged' children, adolescents and adults having a powerful explaining diagnosis, and other groups of exposed children, adolescents and adults as losers in the struggle for resources.

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