

Posters

Abstracts for posters to be presented
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The Norwegian Institute on Intellectual Disability and Community

The Norwegian Institute on Intellectual Disability and Community (Norwegian acronym NAKU) was established in 2006. The background for this is found in the White Paper no 40 (2002-2003): "Removing Disabling Barriers" which states that society faces special challenges in order to provide good and stable living conditions for people with intellectual disabilities. The primary target group for NAKU is service providers and planners in the municipalities, and the aims are to enhance competency in order for the municipalities to be able to provide adequate and individually tailored services. So far, NAKU has established a website that among other information contains a Bank of Knowledge where one is able to find information about people with intellectual disabilities in all aspects of their lives such as living arrangements, work life, health, leisure activities and social relations. NAKU also has published reports on health services for people with intellectual disabilities and has established a network of health professionals and service providers in order to heighten our joint understanding of people with intellectual disabilities who also have a psychiatric disorder.

Presenting this poster, we will inform about our future plans and discuss what role such an Institute will be able to play in order to enhance knowledge and deepen our understanding of how to improve the living conditions of people with intellectual disabilities.

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Environmental Impact on People with Spinal Cord Injury

Key words: Environment, Participation, Barriers, Disability, Spinal Cord Injury

Objective. The purpose of this sequential mixed methods study was to identify and describe the perceptions of environmental barriers impacting the social participation of Icelandic individuals with spinal cord injury.

Method. In the quantitative part the degree to which environmental barriers impact the participation of individuals with spinal cord injury were assessed and the aspects of participation most affected were identified, by use of the Craig Hospital Inventory of Environmental Factors (CHIEF) instrument. Alternatively, a focusgroup interview provided qualitative information to assist in explaining and interpreting the quantitative findings. The 24 participants in the quantitative part were members of the Icelandic Spinal Cord Injury Association, ages 18 years and older. Six participants were chosen for a group discussion in the qualitative part

Results. The most common barriers identified were within the physical environment, i.e., natural environmental elements as well as the design and layout of buildings and places. Other main barriers involved programs, services and governmental factors. This included lack of transportation availability, assistive devices, as well as inclusive governmental programs and policies. Significant difference was found within the total score of the participants depending on their age, residence and gender where participants in the age group 48 – 57 years old and living in the capital area reported less hindrances in their environment than others. Moreover, men reported more barriers concerning governmental factors than women.

Conclusion. The results of the study reveal how the participants experience effects of the environment on their everyday lives. The findings can be useful in planning and implementing services for individuals with spinal cord injuries. They may assist Icelandic authorities in understanding and ultimately removing environmental barriers for people with spinal cord injuries.

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Children with short stature in Norway. Health status reported by their parents.

Abstract

Background: There was a lack of knowledge about children with short stature in Norway. A survey was therefore performed to examine the health status of children with short stature and compare with health status of other children.

Methods and materials: Child health questionnaire (CHQ) parent form was sent by mail to 31 families with children with short stature, age 5-15 years who were registered at the TRS resource centre for rare disorders. Completed questionnaires were received from 20 parents (65%). Mean age of the children was 9.2 years, there were ten girls.

Results: The short stature children showed significant impaired health status in the physical subscales compared with the norm from USA, especially in the physical function ($p < 0,001$), bodily pain ($p = 0,004$), physical ($p < 0,001$) and emotional role ($p = 0,006$) and the children's self-esteem ($p = 0,015$). The children condition influenced the parents emotionally ($p < 0,001$), the parents use of time ($p = 0,030$) and the families' activities ($p < 0,001$).

Conclusion: Short stature will influence both the child and their families in different ways. Parents report declined physical function and declined self esteem of their children. It is important that professionals in the health care system and school system know this and meet the children and their families with understanding of the emotional strain and the practical efforts that may be associated with these conditions.

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Personalisation in Practice

Key words: communication, personalisation, support, participation.

Objective/Purpose

This poster will present research findings from an inclusive project that explored the skills needed by personal assistants of people with learning disabilities.

Personalisation is the new mantra of social care in the UK and in Northern Europe. Yet the fabric of people's lives depends on the actual interactions they enjoy with those around them – personalisation has to be enacted in everyday life. Disability research does need to relate directly to people's lives, and one way of doing this is to for the work to be actually carried out in partnership with disabled people. The objectives of this study were to:

- a) discover what direct payments users with learning disabilities wanted from their personal assistants (PAs)
- b) describe in detail how those skills were played out in everyday encounters.

Method

Two people with learning disabilities worked with the author in an inclusive team, and were paid as central members of this research project. This project took place in a Centre for Inclusive Living, an organisation run by disabled people, and was led and advised by disabled people throughout. The study used a range of methodologies, but this poster will focus particularly on the final phase, which used video interaction analysis. Fourteen pairs of people with learning disabilities and their PAs were filmed, as they went about their ordinary activities, and the co-researchers then decided which extracts were significant to them. A detailed conversation analysis was carried out, which followed the themes identified by the co-researchers.

Results and Conclusion

Supporters delivered good support when they did these five things: 1) showed respect; b) gave people choices; c) were friendly; d) gave good advice; e) helped people to speak up. The ways in which they did these things often needed fine-tuning with the person they were supporting, and body language was very important. Personalised support means knowing and sharing information and background, and people drew on shared information in their exchanges. This poster will be illustrated with still-shots from the research and from the training pack which was produced by the team.

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Naoko IWATA ,Okinawa International University, JAPAN, Japanese Independent Living Movement.

Present and Future of Japanese Independent Living Movement: Analyzing from disabled people's perspective

Independent Living Movement has become global phenomenon. As for Japan, philosophy and practical action have been introduced from western countries in 1980s, especially from USA and UK. During developing their strategies, first Centre for Independent Living (CIL) started in 1986 in Tokyo, and gradually spread among nationwide. The number reached 134 in 2005, and each centre became one of the pioneers to provide user-led and right based community services.

However, it is really difficult to transform from paternalistic and professional-oriented system to user-led system. There are individual, medical approaches that still occupied all range of disability policies, and also, it has excluded disabled people from mainstream and has kept them politically powerless. Furthermore, Government brought a new social welfare law in 2005 without having enough discussion with disabled people. It put a greater burden of self-responsibility on disabled people, and many of them have to abandon to live independently. In contrast to ideal goal of disabled people, it is difficult to break down the structural barrier.

But, Japanese Independent Living Movement activists never give up, and strengthen the campaign to realize a really equally and right based society. They are now campaigning to abolish the useless problematic law, and create enforceable anti-discrimination law that appropriate The UN Convention on the Rights of persons with disabilities in 2006, which came into force on May 2008.

To fulfil the purpose, it is important to grope for the direction toward this new step by looking back history of Japanese Independent Living Movement. Undoubtedly to say, it is valuable to look back on the history of Japanese policies from disabled people's perspective. In order to contribute a part of this purpose, I interviewed disabled activists who are the leaders of nationwide user-led organizations. I asked them to review the policies for disabled people, and also asked them to presume the next step and its tasks.

As a result, they emphasized that there were big changes after philosophy of Independent Living Movement was introduced and spread among disabled people. But, they also thought it important that disabled people's movements before the Independent Living philosophy came, such as Aoi Shiba no kai, were the foundation/basis of Japanese Independent Living movement.

Also, disabled leaders thought it important to strengthen local CILs as hub of Independent Living Movement. To success the meaningful involvement in the process of policy making and realize the active social policies, it is indispensable to strengthen local CILs not only because developing and enjoying independent lives, but also because bottoming up the voices of disabled people. We need further review about the history of Japanese Independent Living.

(This poster presentation begins with parallel review of both history of Japanese Independent Movement and history of main policy for disabled people. Then secondly, shows the analysis of interviews.)

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Theatre nonSTOP

Theatre nonSTOP; a theatre for art and empowerment

Participants of Theatre nonSTOP

Theatre nonSTOP is a theatre for people with intellectual disabilities. It's a theatre with 15 actors with intellectual disabilities, 1 organizer and 2 project leaders. The theatre is also arena for 10 social educator students doing their practice studies. With this poster-presentation participants from the theatre will show how we work together making art. Theatre nonSTOP is established as a place of work, and the main goal is to develop a theatre based on empowering communication, establish an arena where social educator students can learn how to participate in a dialogue based on empowerment and equality. We want to 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.

Participating in a conference is a way to communicate; and it is an opportunity to tell by ourselves and not just through others. This is a way of empowerment. We want to tell how we in Theatre nonSTOP are working together with professional instructors and play writers; and also how we cooperate with the University College in their education of social educators. This cooperation gives the actors the possibility to get education in drama/theatre, music and dance at the University College together with the ordinary students.

We also want to show the importance of being able to have the possibility of choosing theatre as work for a group of people that traditionally have few options for choosing between different working places, because of their lack of traditional working abilities. Still they may have special abilities for making innovative theatre.

The poster will be presented by actors with intellectual disabilities together with organizers. 2 actors and 2 organizers.

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“User participation and involvement in rehabilitation, - a qualitative study of everyday life with a mental disability”

Background

User involvement has assumed a prominent position in national and international social policy and intervention within the health care sector for several years, and the user`s active involvement is part of the basic values in mental health rehabilitation. Literature on this area of research mainly addresses implementation issues; however knowledge on the user`s perspective remains scant. Their experience of participation and involvement in the process of rehabilitation and the interplay with the professionals remains unexplored.

Aim

The aim of the study is to gain knowledge about how the user`s experience participation and involvement in mental health rehabilitation.

Material and method

The study is designed as a field study performed over a year in two supported housing units in the community, including 12 participants with a mental disability who is taken part in mental health rehabilitation. The methods used in the data collection were participant observation, ethnographic interview (James Spradley) and group interview. Paul Ricoeur`s phenomenological hermeneutical interpretation theory were inspiration for doing the qualitative analysis, following three methodological steps; naive reading, structural analysis and critical interpretation. Theories about rehabilitation, self-determination, recognition and learning were used in the critical interpretation.

Results

The preliminary results of the study will be presented, including a discussion of the main findings and the implications for clinical practice and future research.

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Public services concerning children with special needs

Key words: Public services, Early Intervention, Young children, Special needs, Families

Aims:

The overall aim of the project is to explore and interpret the official goals in public services towards young children with special needs (age 0-6) and their parents and how it meets the needs of the target group. An additional aim is to generate knowledge and work out a service model based on the needs of the consumers and current resources.

Method:

1. Reports, statements and agreements that lay the ground for public services will be reviewed.
2. Services within the three main components of the welfare system; health-, social- and educational services will be analysed considering how they intend and claim to support and facilitate young children with special needs and their families.
3. Interviews with parents, personnel and service providers, analysed by means of qualitative content analyses.

The impetus of the research comes from experience of working as a professional in this sector of the welfare system in Iceland for about 15 years. The claim of the welfare system in Iceland regarding young children with special needs is that all children shall have equal opportunities and be met on an individual bases in all aspects. In contradiction to this, parents often express their disappointment with how their and their children's needs are met and they often express their sense of having to explore the system and find out their legal rights on their own. This opinion crystallizes in the establishment of "Sjónarhóll" a counselling center for parents of children with special needs in Iceland, operated on behalf of four associations concerned with the rights of children with special needs and their families.

The current point of view in this project is the Developmental Systems Approach to Early Intervention. This framework provides a rationale for many structural components and principles, with a strong developmental orientation. Additionally emphasis is placed on accurate information and proper resolution for the families.

The researcher is in the early stages of her doctoral studies and is working on the research proposal.

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The inclusive school - an epistemological perspective
Ph.D. project starting February 2009

Key words: inclusion, inclusive school, replacement, deviancy.

Objective/Purpose: The focus of this project is to analyze inclusion as a discourse, and the role of the inclusive school with special attendance towards pupils from 'residential homes'. By doing so I intend to analyze how the inclusive school can be developed, so that children from residential homes can benefit from it

This project presumes, that the fact that replaced children don't manage as well in school as their peers can be interpreted as a consequence of the sharp distinction between the social pedagogical effort cared out by the social service system, and the effort cared out by the special needs education. The effort to help pupils from residential homes is thus affected by two distinctive approaches instead of one overall-oriented effort. The inclusive school potentially represents such an overall-oriented effort.

The project' aims at qualifying the role of the public school in society with special attention towards the challenge to include children from residential homes into the public school. The interaction between inclusion and the role of the public school involves discussions about the purpose of inclusion: is the ideal of inclusion foremost for those who should be included, or does inclusive practice involve general educational qualities such as 'learning citizenship' that all pupils will benefit from?

Method: This project is focusing on inclusion as a prism, where various educational strategies like general educational theory, special needs education and social education meet and crystallize. This project assume that a focus on the emergence of these strategies, their societal functions, their conceptualization of the child with deviances can benefit an analysis of the role of the inclusive school in the late modern society.

My project concerning the inclusive school aims at interpreting the role of the traditions and differentiation between general educational theory, special needs education and social education, as social and political ways of conceptualizing the disabled child and 'the placed child'. The starting point of this project will be the post-structuralistic tradition. According to Foucault's version of this tradition it is neither possible nor interesting to seek to establish continuity in history. Changes in history will examine fractures and events.

Perspectives: What will be the implications of the research? The result of the research will create knowledge about various educational discourses articulations of the child, especially in relation to normality and deviancy. I assume that the research will be relevant not only to researchers, but also to professionals within schools, day-care centers, public health services and social workers. The research relates to the ongoing pedagogical discussion about children's right to citizenship and participation in the school and in society as a whole.

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Results and experiences from a systematic review on vocabulary selection in communication aids.

BACKGROUND AND PURPOSE: This poster will present results and experiences from a systematic literature review concerning various aspects of vocabulary selection for non-speaking children with disabilities. The study was initiated to gain more experience with applying the principles from evidence based practice in the area of AAC (augmentative and alternative communication) and to investigate whether this approach was helpful to qualify practice. Furthermore, we had the hope of extending our knowledge on vocabulary selections for communication aids.

Communication aids such as communication boards and books and speech generating devices can be an important mode of communication for non-speaking children. However, giving children with disabilities access to low and high tech communication aids give rise to a number of questions among clinicians in relation to vocabulary selection. What should the child be able to say? How many vocabulary items should the child have access to? Are single words or phrases to be preferred? How should the items be organized?

METHOD: It was decided to conduct a systematic literature review to investigate this further. Based on a focused research question, search words were identified and used for the following database search via Dialog: PsychInfo / ERIC / Medline / Social SciSearch / Embase / Dissertation Abstracts online / Pascal / AMED / Biosis Previews / Education Abstracts / Scisearch / CINAHL. This resulted in 393 references. In addition, handsearches of webpages and handbooks and snowballing resulted in further 48 references. After having deleted duplicates, reference titles and abstracts when available were then screened by two reviewers independently, leaving 72 possible references. Abstracts and when necessary the entire articles were assessed by two reviewers independently, based on a set of inclusion criteria. This resulted in identification of four articles. The scientific quality of these articles was then appraised by three researchers, each article being appraised by two researchers independently, after which all four articles were maintained in the study. Finally, the five reviewers discussed the applicability of the study results.

RESULTS AND CONCLUSION: Based on the identified four articles it was not possible to do a meta-analysis or give evidence based directions on how to select and organize vocabulary for children without spoken language. There was a lack of studies that clearly addressed the aspects of the focused question, and there was a lack of studies that described results after a chosen intervention strategy. The conclusion is that what is most evident from the three studies concerning content is that it will always be necessary to consider an individual and personalized vocabulary.

Results from the studies gave indications and inspiration for clinical practice. However the systematic literature review did not provide conclusive evidence on how to address the complex process of vocabulary selection when introducing communication aids for a very heterogenous group of children with multiple disabilities. Existing research in this area can only contribute with very limited directions that can be generalized to a larger group of individuals. Based on the experiences from the project, it is recommended that other approaches are considered alongside with literature reviews.

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Mikkel Bundgaard & Inger Stoltze Poulsen, Ethics Committee, Danish Handicap Association.

Stigmatization of people with disabilities

Ethical Committee of the Danish Handicap Association (DHF) has for years focused on the ethical issues and dilemmas arising in connection with the rapid and accelerating development in biomedicine, which directly or indirectly affect the members of DHF. Issues the committee has worked with include diagnostic on embryos, genetic engineering and euthanasia. We represent a broad group of people with physical disabilities.

We believe that the language used in the research context often is simplistic and stigmatizing to receive in relation to the roles and positions of people with handicaps.

The background for research on disability is that we differ from the population in three areas:

1. We can not participate in society on equal terms with others because of the lack of physical accessibility in society.
2. Since many of us often have visible disabilities, the reaction of our appearance often is negative in the meeting with other people (if they have no experience in the area).
3. We can also distinguish us in our own self-image, depending on our personal history and what situation we are put in.

The intention must be to gain insight and to remedy problems and thus minimize the handicap as much as possible in every way.

Language and terminology

Language affects the frame of reference, which is the basis for what you perceive as "normal." An example of this is how to use the term handicap. According to the UN definition a handicap is the combination of a disability and a barrier. So if there is no barrier, then the handicap is reduced to a disability, and thus there is, at best, no real handicap anymore.

In the media and the wider public are people with a handicap often referred to as disabled. This will focus solely on the person's reduction instead of the surroundings, which are obvious to change to reduce the handicap. The public's ideas of people with disabilities are often one-sided and the group is often referred to directly negatively. "The disabled" are helpless individuals. They are often a social / psychological burden to their surroundings and especially a financial burden to society. This view is reflected by the stigmatizing language by which the group is mentioned. This language, unfortunately, also slipped into the scientific community, where the group assigned passive and negative roles and positions. The worst thing is that the researchers rarely consult the group that holds the experience to be outsider. The group that in the first place was the one intended to be helped. This is to stigmatize and isolate the group further. It is unfortunate when this happens in the scientific community as scientists because of their status, often are seen as professionals who have a patent on the truth. It need not be truer, simply because it comes from a researcher.

Incorrect language betrays a lack of knowledge / experience in the field and can lead to that important points are lost and focus comes on something other than it should. It is important to allow people with handicaps to be heard, so we can contribute to the nuanced language we find so important. A handicap is not solely a problem of the one who got it. It is an impairment, which in interaction with the environment becomes a handicap. Therefore, all have a responsibility to how people with handicaps see themselves.

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Marit Haugenes, HINT

“Better life when I’m active”

“Better life when I’m active” is a project meant for persons with developmental disabilities, their families, professional helpers and students. The project was initiated of the organisation NFU, Norsk Forbund for Utviklingshemmede, the Norwegian Association for the Developmental Disabled. Our main contribution in this project is to focus on the importance of diet and activities in order to increase the quality of life for persons with developmental disabilities.

This issue is highly relevant in general in the community, and should also be relevant for people with developmental disabilities. The experience is that they need some special assistance for coping with their choice in these questions. People with developmental disabilities often need support in their life`s. Families, professional helpers, students and so on is therefore important groups in this project. We work together with diet teaching and activities all these groups in three different municipalities. In each municipality ten people with developmental disabilities, their families, professional helpers and students are participant. Our method in this work is action research. Quality of life, and each person`s individual wishes have focus, and we want to develop knowledge in how to prepare this topic for persons with developmental disability. In order to make choices, persons with developmental disabilities need to be prepared the matters in understandable approaches. By developing knowledge and methods for the families, professional helpers and students they can be able to give assistance in daily living.

This project is based on cooperation between NFU, Nord-Trøndelag University College (HINT) and the municipalities of Verdal, Namsos and Inderøy. HINT is responsible for carry out the work.

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Namsos Snoezelen center; an arena for practical studies for social educator students.

Namsos Snoezelen center was established in 2003 in cooperation between the municipality of Namsos and the University college of Nord-Trøndelag. Snoezelen is based on multisensory stimulation, mainly used for people with mental disabilities. The idea is to have different rooms designed to deliver stimuli to various senses, using lightning effects, color, sounds, scents, music and so on.

One of the arguments for the university college to get involved in this establishment was the lack of arenas for practical studies offering alternative methods working with people with different kinds of disabilities. It also gives the university college an opportunity to work closely together with the municipality and the practitioners in the community.

The Snoezelen environment is safe and non-threatening. Children and adults with disabilities or other limiting conditions can enjoy gentle stimulation of the primary senses. Participants experience self-control, autonomous discovery, and exploration-achievements that overcome inhibitions, enhance self-esteem, and reduce tension.

Namsos Snoezelen center offers an arena for activity and experience based on coping with your difficulties in a non-directive therapy. There is no focus on therapeutic outcomes – it's the experience in itself that is important and the advantage that lies in that this is a method that not relies on verbal communication. This makes it useful also for people without verbal language, or just for anyone that wants a time of pure pleasure. Namsos Snoezelen center are free from the expectations of others and away from the pressures of directed care, our main focus are recuperate and relax. In that way, Snoezelen can be used by everyone.

Namsos Snoezelen center is used by people with intellectual disabilities, autism, mental illnesses and Parkinsons, as well as for those with challenging behaviors, acquired brain injury, and other conditions. In addition, Snoezelen is gaining momentum in the mainstream population as an antidote to stress.

This is also an important arena for research. Research for qualitative inquiries based on observation and narratives from the people experiencing snoezelen.

Research has shown that multisensory environments offer a wealth of benefits, often affording the participant and caregiver an opportunity to improve communications, enhance their understanding of each other, and build trust in their relationship.

Over the past fifteen years, Snoezelen has grown into a worldwide movement in over 30 countries with thousands of installations, a worldwide foundation, national and international conferences, and international research projects. However, we are still at the beginning of exploring applications for this extraordinary and successful concept and, of understanding the responses of people with disabilities and other limiting conditions to these stimulating and fascinating sensory environments.

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