

**Reports of the conference “Diversity in Quality of Life”
December 2-4 2010 Amsterdam
Disability Studies in Nederland and VU University Amsterdam**

Reports made by: Wanda Liebermann, Veroniek Maat, Silke Hoppe, Judith Jansen, Lieke van Heumen; native check: Chris Pelleboer; editing: Marloes Moraal

We are very grateful for the financial support by UWV in making the reports of the conference possible.

Keynote presentations

1. Openingsspeech

Sam Galesloot 1)

Sam Galesloot uses the term “Quality of Existence” instead of “Quality of Life”, for he wanted to stress that Quality of Life is not only about medical issues but mostly about the whole of each person's life.

Quality of existence is about living your life in its full potential. He stated that there is no difference between his life, living with severe disabilities, and other people's life. It's about enjoying life, reaching for new goals, overcoming barriers, it's about love and positivity.

Sam Galesloot's situation is, from a 'objective' quality of life perspective, easily judged as not good; Sam himself judges his quality of existence with an A-minus. Quality of existence differs from person to person. The theme of the conference “Diversity IN Quality of Life” is therefore well chosen, according to Sam.

1) = NB 3 weeks after the conference we got the very sad news that Sam Galesloot died in his sleep. We are very honoured that he was able to start our conference with his eloquent speech.

2. “Differing ways to think about the controversial term “quality of life.”

Dr. Adrienne Asch

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Many people in the field of Disability Studies, and many disability advocates, understandably fear that “quality of life” judgments made by people unfamiliar with the lives of those with disabilities have been and will continue to be biased against them, as demonstrated by dominant bioethical statements about starting or continuing lives that will include disability. Such negative perceptions can adversely affect access to societal resources and life outcomes. Thus, societal beliefs about how a person's disability leads to a reduced quality of life can be used as a self-fulfilling prophecy, to guarantee just such a result. But when viewed from the perspective of people with disabilities, quality of life ideas can be useful guides to assessing whether a person with a disability is living

well or poorly. I will argue that the components that go into assessing quality of life for the general population can be applied to people with disabilities and that if they are so applied, we can get useful information to help people with disabilities improve their lives. Such quality of life assessments can demonstrate what society needs to do to maximize the opportunities for people with disabilities to lead rewarding lives. The talk will include examples of ways that nondisabled and disabled scholars assess how congenital or acquired sensory, physical, or cognitive disabilities affect an individual's life. Although I will suggest that disability may not be exactly like such characteristics as race or gender in having no negative life impact apart from adverse discrimination, I will argue that nearly all of the presumed negative facets of life with disability can be ameliorated by reformed societal practices.

3. “The End of Normal: Diversity and Disability”

Prof. Lennard J. Davis

Disability Studies, Medical Education, Department of English, University of Illinois, Chicago, United States

“The End of Normal: Diversity and Disability” argues that the older concept of “normal” has given way to the idea of the “diverse” in the past twenty years. Diversity has employed a neoliberal proclivity toward “choice” as a factor in identity politics—one can choose to be almost any identity now. We don’t ask people to have a “normal” identity any more, we only ask that people celebrate diversity. However, the only area in which normal still holds sway is in medical discourse, and to the extent that disability is located in that discourse, normal will remain the operative word. But elsewhere “normal” is suspended by a permanent state of exception defined by a reign of diversity.

4. “On a fourth way for disability: blind photographers and down artists”

Benjamin Mayer-Foulkes

17, Institute of Critical Studies (Mexico)

On the basis of Jacques Lacan’s propositions concerning his Four Discourses (1968-69), I suggest there are four overall ways of inhabiting and approaching “disability” (which can also be conceived as four matrices of development). In the wake of the French psychoanalyst, these can be characterized as Religion, Science, Art, and Psychoanalysis. Each of them represents a distinct configuration of power, knowledge and experience. Whilst we are amply familiar with the ethos of the first three (Religion, Science and Art), beyond the known forms of psychoanalytic clinical and critical work, as regards disability the fourth way (Psychoanalysis), qua social bond, remains largely unexplored.

The practice of blind photographers provides a commanding example of the nature and fruitfulness of this fourth way, and of its particular contemporary importance. Notwithstanding the character of their artistic projects, their very activity interrogates a host of received ideas about blindness and the image, and clears the way for novel forms of experimenting blindness personally, and appraising it socially. For instance, cultivation of the visual arts can, and should be promoted amongst the blind. Conversely, the blind can, and should be taken in by centres of visual learning focused on design, photography, art, video, animation, cinema, etc. Not in the name of “integration”, but in an effort to alleviate that most perilous form of blindness, so common amongst the sighted: blindness to blindness itself.

The fourth way for disability is also illustrated by the way in which the noted drawings, engravings and oil paintings by the artists of the Mexican School of Down Art disprove contemporary and widespread forms of vulgar and not-so-vulgar geneticism (i.e. the ideological reduction of personal

and social traits to genes, with a disregard for the crucial rôle played in human affairs of historical, cultural and psychic factors). Too often, medical prognoses of what the life of the new-born with trisomy might be like are gratuitously negative. Since such utterances seem to bear the full weight and prestige of “science”, they can play a sadly foundational function in the lives of those with Down syndrome. They can even turn into self-fulfilling prophecies, severing the bond between mothers and their children to the point of conjuring psychotic formations amongst the latter, whose origin has no relation whatsoever to the syndrome as such. The compelling variety of Down art and artists powerfully dispels genetic homogenization and its phantasms. Thus it is of crucial importance today in and beyond the domain of intellectual disability, and even disability as such. Whilst generally associated with a lack, disability always involves a paradoxical surplus of psychic, cultural and social capital whose ultimate power —and traditionally perceived threat— is to unveil the artificiality and fragility of social “normality”. The horizon pertaining to this fourth way of inhabiting and approaching disability opens a wide array of theoretical and historical questions, whilst allowing at the same time for innovation in policy and practice. Mine is an invitation further to understand and explore the possibilities associated with this fourth approach of disability, in psychoanalytic key.

Further references:

Resources on Blind Photography: www.honoriscausa.17.edu.mx

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5. Quality of Life: reflections from evaluation of community-based rehabilitation projects in India and China

Dr. Maya Thomas

Asia Pacific Disability Rehabilitation Journal, Bangalore, India

Theme

Multi Cultural Perspectives on Quality of Life

Aim

The aim of this presentation is to highlight and compare findings from evaluations of community based rehabilitation (CBR) projects from India and China, and to derive some conclusions on quality of life of persons with disabilities in these projects, based on the principles and key components of the CBR Matrix from the newly launched WHO CBR Guidelines.

Methods

The evaluation findings used for the purpose of this paper were based on 2 evaluations led by the author: a community mental health project implemented by a non-governmental organisation in India; and a provincial CBR project implemented by a semi-governmental organisation in China.

Both evaluations assessed relevance, effectiveness and sustainability of the projects. In both evaluations, voices and lived experiences of persons with disabilities were documented.

An attempt was subsequently made to see how the findings from the 2 evaluations were in line with the principles and key components of the CBR Matrix of WHO. The principles are participation, inclusion, access, self advocacy and sustainability. The 5 key components are health, education, livelihoods, social, and empowerment.

Results

While there are differences in the way the 2 projects are conceptualised, organised and implemented, both have made a significant difference in the lives of persons with disabilities. There are differences in the way their work outcomes reflect the principles of the CBR Matrix, especially participation and inclusion. Each project has defined 'participation' and 'inclusion' according to the context in which it operates, and has carried out activities accordingly. Activities of both the projects encompass all 5 components, with differing emphasis. In both projects, poverty is a major challenge and access to basic services has been a significant outcome. The presentation will highlight the key findings from the evaluations, along with some voices of persons with disabilities, to reflect the CBR Matrix principles and quality of life.

Conclusions

Bringing about changes in quality of life of persons with disabilities as reflected by the CBR Matrix principles and components, is highly context dependent and may be difficult to standardise across cultures. The way 'quality of life' is understood by poor communities who lack access to basic services, is likely to be very different from the more developed ones.

6. "Quality and narrative"

Hans Reinders

VU University Amsterdam, Amsterdam, The Netherlands

Quality of life has become a major concept in social services and health care for people with disabilities. Over the years the use of this concept has evolved from a personal support oriented to a policy oriented approach. Quality of life is nowadays a key concept in how governments, healthcare insurers, and service providers assess what patients and clients receive in terms of care and support. With this policy oriented use comes a particular method of assessment that favors objective measurement of quality indicators. This paper will explore the logic of measuring quality and examine how it affects the content of what quality is supposed to be. The result will be contrasted with a person oriented approach that uses the person's story as a key concept. Finally the paper will explore how both methodologies affect the evaluation of diversity in quality of life.

Oral presentations

Concurrent sessions I

Friday, December 3 from 13.30 - 14.30 hrs

Session A. To be or not to be

1. Cochlear implantation and genetic research: blessing or curse?

Marcel Broesterhuizen

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Marcel Broesterhuizen presents an ethical and theological reflection on the difference between hearing and deaf people in relation to the ethical evaluation of cochlear implantation of young deaf children and genetic research of deafness. In his presentation Broesterhuizen quotes “to be criminal to withhold a deaf child a cochlear implantation”. For hearing persons, these are important contributions to deaf people’s quality of life, and as such an ethical necessity, whereas most deaf people themselves consider them a threat for quality of life. When cochlear implantation was developed it sparked serious discussions as to whether one would violate a healthy child or one would take the risk of the child being expelled from the deaf community.

Broesterhuizen explores the background of this difference and proposes a way of dealing with this difference in daily contacts between hearing and deaf persons. He considers that cochlear implantation can be a better hearing asset but one would remain a deaf person and one can still be proud to be part of the deaf community.

He concludes that both the hearing and deaf worlds will not merge because they both have their own worth’s. The hearing and the deaf views on cochlear implantation and genetic research have their own logic in different cultures and different worlds. The difference between these two competing views on deafness and its treatment cannot be resolved by an exchange of arguments with one winning view as a result, but can be dealt only with in continuous dialogue and negotiation. Therefore he advises to analyze the life stories of the proponents of oralism and cochlear implantation.

Broesterhuizen adds in the discussion that It’s been recently proven that when a child is given a cochlear implantation before the age of one, the child will develop as a hearing child. This results from brain’s elasticity. This conclusion will provide a totally new point-of-view for parents to consider.

Keywords: deafness, cochlear implantation, inclusion

2. What using embodied knowledge does to the quality of life of the researcher: personal reflections

Karin Mogendorff

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Karin Mogendorff did anthropological research among people with congenital neuromer impairment, an impairment she is suffering from herself. She wrote her thesis using her own embodied knowledge to discover how this affects the scientists’ well-being or quality of life. She tries to explain the long-term effects of working with experiential knowledge on relationships (friendships, family bonding, etcetera) in order to further our understanding of the consequences of the choices that come with using one’s own experiential knowledge as a professional.

She concludes that embodied knowledge both empowers and makes the scientist vulnerable in several ways. This partly depends on the extent one uses one's own embodied experience as a research tool. Mogendorff explains that one of her ways of dealing with negative responses to her impairments is writing and publishing about it. This helps her to better understand the process of social exclusion and stigmatization of disabled people; it invites disclosures or comments from people you know or have known. This is an informative process but not necessarily pleasant. She also concludes that embodied knowledge can be rewarding as well. She experienced that some of her own personal coping strategies for handling negative inferences of others didn't work anymore and she needed to develop a new way of coping. In this way she turned personal experiences into a resource. Finally she concludes that both vulnerability and empowerment may be partly produced by ways of using embodied knowledge to rearrange 'traditional' boundaries between the private, the public and the professional.

Keywords: embodied knowledge, research, social exclusion

3. A reflection on *empowerment*: insights from theory, literature and HEE practice

Jenny Boumans and Marianne A.J. van Bakel

Trimbos-instituut, Section Reintegration, Utrecht

Jenny Boumans reflects on the frequently used term 'empowerment' in relation to disease, (psychiatric) vulnerability and disability. She presents a conceptual framework of empowerment based on (historical) theory and first results of a literature review on empowering interventions in the context of care and welfare. Boumans explains how empowerment is often used in a shallow way but is in fact a complex multidimensional concept that essentially is about an individual's potential to be a subject of their own life. The meaning of empowerment in this context is learning to use your own power/strength to regain control over your life. It is about making your own choices and implementing changes. Both creating awareness and taking action are necessary steps to do this.

She argues that empowerment has both social and intrinsic consequences. It provides individual control to one's own situation and creates independence. It raises the question how do you become a subject of your own life. This results in a double battle. Empowerment provides freedom of choice for one's own situation and provides choices on how to deal with one's disability. But empowerment also increases the battle between being a subject or an object in your life. This raises a dilemma. By empowering yourself are you yourself or are you an participant?

Boumans argues that you need to focus upon the individual subject and the context as well. How does empowerment help you to become a subject? And how can it develop initiatives that create conditions for empowerment?

She presents an example of the HEE programme. HEE is the (Dutch) abbreviation of 'Herstel, Empowerment en Ervaringsdeskundigheid'. The English translation is: Towards Recovery, Empowerment and Experiential knowledge. HEE is developed by long term mental healthcare providers and consumers and combines the strategies and methods of user initiatives which are thought to account for their success.

HEE works with constructed and shared life stories. Participants create recovery stories by writing we-stories and I-stories. Every individual writes his or her own story down and rewrites it. He or she receives feedback from others to clarify his/her story. In this way, people learn from each other and share knowledge. This provides conditions for empowerment.

Keywords: Empowerment, identity, participation

Session B. What distinguishes disability studies?

1. About modern patients, medical knowledge and the place of experience

Jeannette Pols

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The presenter stated that in the emancipation of persons with disabilities, there is a difficult relation with the medical profession. On one hand of the spectrum, medical discourses are rejected. On the other hand there is collaboration with the medical world. In both cases, there is a neglect of particular forms of knowledge, and or lived experience in particular. The presenter studied this knowledge or experience of people with chronic illness and focused on how people develop and coordinate different types of knowledge and experiences.

She demonstrated three dominant configurations of the relationship between patients and physicians. In the first configuration the patient stands in opposition to the doctor. The doctor is the expert and represents knowledge, facts about the body and the medical science in general. The patient is the lay and represents meaning, perspective and the social sciences in general. In the second configuration the patient stands alone, and has expertise and information because of education and the use of the internet. The knowledge of this type of patient is medical in nature. In the last configuration, there is a power differential between the patient and the physician. In this case, knowledge is irrelevant, but the patient should gain more power and choice and has certain preferences and demands.

The presenter argued that within these three different configurations it is difficult to study the knowledge of patients. Within the first relationship between the patient and the physician the patient has no knowledge. Within the second relationship, the patient has the same knowledge as the physician. In the third relationship knowledge and technologies are irrelevant. In this alternative, the patient and doctor have different experiences and scientific knowledge opposes practical knowledge. The practical knowledge of the patient is embodied knowledge. Scientific knowledge needs to be translated into practical knowledge. To that end collaborations need to be made and different research methods need to be used.

Keywords: lived experience, chronic illness, relation with medical profession.

2. Disability studies and aging

Lieke van Heumen, MSc.

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The presenter argued that even though more persons live longer with a disability, whether the onset is early in life or comes with aging, there is a lack of integration between disability studies and gerontology. She explained the lack of attention for disability in gerontology, focused on the decline and loss and biomedical paradigms, demonstrated the occurrence of ableism, and argued that developments in the discipline caused a further distancing from disability. Critical gerontologists picked up on these developments and argued that a dialectical vision of aging that acknowledges both disability and able bodies as valid parts of the aging experience is missing. Research and theory on aging that explicitly identifies with the disability studies paradigm is scarce. Critical gerontology scholars have commented on this dearth and stated that disability studies have distanced themselves from aging, mainly because of the centrality of workforce participation in this discipline.

The presenter argued that there are important parallels between disability studies and gerontology. In both disciplines, critiques on medicalized and individualized accounts of aging and disability are recognizable. As well, there is a similar application of an overcoming paradigm identifiable. In disability studies and critical gerontology similar arguments based on political economy and social constructionist perspectives are used to great effect. As well, in both disciplines the importance of individual narratives and lived experience is increasingly emphasized.

The presenter stated that within both disciplines people with intellectual disabilities are overlooked. The impairments in this population are often viewed as the cause of disablement and this population remains marginalized within the social model. Within gerontology research and theory people with intellectual disabilities have not been included. The presenter argued the importance of studying aging in this population because of the many gaps in the knowledge on older persons with intellectual disabilities. Research indicates a risk on social isolation. At this point the presenter discussed the topic of loneliness as an important area of research in gerontology and as a topic with potential in disability studies. In the conclusion she emphasized the importance of combining both disciplines as an interdisciplinary approach in informing both disability and aging discourses. Loneliness in older adults with intellectual disabilities in particular is a topic that can be only fully understood examined in this intersection.

In the discussion more amazement was demonstrated on the lack of attention in gerontology for disability and intellectual disabilities in particular considering the interest in dementia in this field. As well, the work of Jan Walmsley was mentioned and a recently established disability studies research project on dementia at Maastricht University in the Netherlands.

Keywords: aging, intellectual disabilities, loneliness

3. Sharing the loop: A grounded approach to relating to and through medication Preferred medium of presentation

Joan van Ee

Utrecht University, Gender Studies Dept.

The presenter is interested in the intersection between gender studies and disability studies. She explains how within the medical model there ideally is no difference between living with the right medication and living without medication. The experience of long-term medication use does not fit in this model. To investigate these experiences, she interviewed eight persons with a Western European background who have been using medication long-term. Charmazian grounded theory was used to analyze the interview materials.

The presenter demonstrated that her data showed long-term medication use to be a social-relational practice in which for example disclosure is of importance. She stated that the concept of a feedback loop could be applied to the majority of the participants. An interesting example she provided was that of a woman asking for water in a restaurant to take her medication, resulting in questions of waiting staff on the reason of the medication use and resistance in providing water for free. This demonstrates that disclosure does not necessarily mean others will 'share the loop'. The presenter emphasized the need for a social-relational model of medication that focuses on the flow of information among various parties. This should replace a choice model in which only resistance and compliance are options. The presenter mentioned how she expected to become a part of her interviewees' loops. The interviewees wanted to assist the researcher with her project. She emphasized that she is just scratching the surface in exploring her data, which are very rich.

Keywords: medication use, lived experience, qualitative inquiry

Session C. How does disability experience affect quality of life?

1. Make-Believe Streets and Citizens: Building Dutch and Disabled in Het Dorp, the Netherlands

Wanda Katja Liebermann

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This paper revisits the 1962 watershed cultural event, “Open Het Dorp,” Holland’s famous televised fundraiser to construct a community for the physically disabled, and the subsequent village design. On the one hand, Het Dorp offered a new conception of Dutch disabled citizenship, one that added productivity and civic participation to the role of object of others’ care giving. By creating a realm designed to accommodate the physical needs of a particular disabled figure, a wheelchair user, Het Dorp’s utopian aim was to increase the quality of life, through a dramatic increase in choice, self-determination, and positive identity in a new community. At the same time, the conflicted attitudes and paternalistic application of the administrative and physical design, limited the vision to an essentially segregated way of life, constructing disability as a secondary form of social membership, which remained excluded and stigmatized. In this sense, Het Dorp produces a conflicting experience of quality of life for the disabled residents: more sense of belonging and choice, while separated and categorized.

This talk is an abbreviation of a longer paper. It tells one of many socio-spatial stories of Het Dorp. This critical and distanced point of view leaves out, for example, the love most Het Dorp’s residents have for their home. With this paper the author doesn’t intend to reproduce a model of “expert” knowledge that overshadows these other realities. The author’s interest in the intersection of disability and architecture emerged over a fourteen-year span practicing and teaching architectural design, during which she became increasingly curious and perturbed by the disinterest, even hostility, towards developing a more creative mode of theorizing and designing for corporeal difference.

Key Words: architecture, citizenship, utopia

2. Does disability affect quality of life?

Silke C. Hoppe

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In order to understand the experiences of people with chronic disabilities, this paper asks, in what ways does disability affect quality of life? How do people actually experience a chronic disabling illness? Developing empirical data from interviews with a group of multiple sclerosis patients in Dublin, Ireland, the author attempts to develop a more nuanced and structured model of how they cope with their illness. Selecting MS comes with inherent complexities of cross comparison because it is known as the “disease of a thousand faces,” manifesting unpredictable and diverse symptoms in different people.

Chronic illness assaults not only the body, but also the person’s sense of identity and self-worth. Traditional approaches assume that chronic illness produces only negative changes in identity and quality of life. In line with other research that critiques this narrow view, the author counters these expected outcomes with the personal accounts from a group of twenty-two MS patients

In this process, she encountered a number of narratives of how MS is assimilated and understood in the individuals' lives. First, *normalization*, characterized by the phrase, "I have MS but it doesn't have me," maintains that disability doesn't have to be the sole determining factor and that life may continue as relatively normal, especially after an initial adjustment period. This echoes Adrienne Asch's point from her keynote talk that disability doesn't have to affect quality of life. The second narrative, *loss*, is characterized by shock, disgust, anger, and grief—a general inability to come to terms with the disease. This state does reduce the quality of life; however, building on Lennard Davis' comments from an earlier presentation, the question remains whether s/he will nevertheless return to a median QOL grade of 3.5 out of 5. The surprising model the author uncovered is the one of *personal growth*. In this scenario, diagnosis with MS marks a point of departure with the old self, which develops into a different perspective on life, such as "stopping to smell the roses," becoming a better person, or taking the opportunity to pursue previously neglected interests. This last model can be understood as the potential of transformative experience of a chronic illness. This transformation is marked by a multi-stage rite of passage: separation, liminality, and reintegration. In all of these, questions of bodily integrity, attractiveness, identity, intersect with social, gender, and sexual, and other roles.

Liminality, is a key concept for chronic illness because, because one is betwixt and between; that is, one is neither sick nor well, but in this persistent grey zone. Patients realize that not only has their body but their social position has changed. Can one live in a liminal phase long term? What are coping options? The author suggested that one can join disability identity/group, get better, or hide the illness (though, this is not possible with all illnesses.) Reflecting on one's own life, standing still and self-awareness are means for leaving and transcending liminality. In response to an audience question whether reidentification is a key in this transformation, Hoppe suggested that there are different ways. Another audience question wondered, how does she manage to keep the specificity of the different lives if she calls it all "liminality?" She suggests that people are dealing differently with it, but all are in some stage of liminality

Key Words: transformation, liminality, multiple sclerosis

3. Quality of life: measure or listen

Dick L. Willems

Academic Medical Center / University of Amsterdam

Due to the shortness of time, professor Willem began with his conclusion, which is his overall message: real Quality of Life means something different from the medical (quantitative) definition. And his research offers some warnings! You can decide to measure it, but you have to listen to the narrative behind the checked boxes on the questionnaire. Listen before, or even instead of, measuring. What does this then imply about what measurement is?

QOL measurements in medicine began in oncology studies. Because treatments reduced cancer, but also made people miserable, QOL was used to follow the scheme of medication trials, which also meant that it had to be quantifiable. And this is where the problem originates: with QOL as a scientific concept. Using two trials, one of heart failure patients and one of cancer therapy prior to radiation therapy, the author describes the ways in which conflicting stories emerged between the quantitative QOL measures and the parallel narratives that people provided. It turns out that the questions do not capture the nuances or address people's lived experience. Limited questions, inapplicable topics, and consistent misinterpretation of meanings undermine the possibility that the questionnaire can capture actual QOL. The paradox that this reveals is that there is a lack of comprehension for what QOL is. There is a mismatch between medication trial mode and real situated lives. Thus, if you study QOL, listening and measuring produce different realities.

Audience questions elicited a discussion of the reception of this research in medicine. Willems admits that his research can't be published in medical journals because its very premise

undermines accepted QOL measuring practices and, by implication, challenges fundamental questions about how trials and medical models are set up. Moreover, such research questions positivist approaches altogether—what is objective versus subjective. It challenges how measurement—the basis of scientific knowledge—can be reliable. The author suggests that to properly analyze and present this data, questionnaire numerical results should be published alongside the stories, to enable another reading or deeper interpretation that nuances or contradicts the numerical “truth.” The solution could be to combine studies instead of choosing among them.

Key words: measurements, narrative, objective

Session D. Multi Cultural Perspectives on Quality of Life

1. Diversity in quality of life among disabled people and standardized approaches.

Jos Philips Ph.D.

Department of Philosophy/ Ethics Institute, Utrecht University, The Netherlands

Quality of life is a broad concept and a diversity of approaches can be taken. The approaches are in some sense ‘standardized’ as they are quite general, almost exclusively objective or even explicitly simplified. These standardized approaches do not acknowledge the diversity in quality of life as it is experienced by people with disabilities. Philips notes the discourse of human rights which people with disabilities face and are often standardized. QOL calls for dimensions of diversity including cultural diversity, individual diversity, objective versus subjective diversity, level of generality. QOL needs a focus on narrative approaches. Diversity indicates different stories about life. When one looks at QOL and human rights one should ask the question: are the interests of people with disabilities protected by rights? Within standardization this person is protected against standard threats which can be applied for ‘normal’ people, as they are related to the idea of normality. The interests can be predicted and general rights apply. The 1948 Diversity Declaration was introduced but still there needs to be a standardized approach to human rights. Three options appear, continue the system according to the discourse, forget about the problems or create a new discourse. The current society chooses to continue with the discourse. If the discourse becomes better and refined it could work and acknowledge diversity. People are motivated by persons and narratives and therefore social analysis within the discourse could work. People with disabilities need to be involved as well as their subjective evaluation of QOL.

Keywords: QOL, diversity, standardized approaches, discourse of human rights, narrative approach

2. The *Quality of Quality of Life: A History of Bureaucratic Assessments of Western Disabled Children*

Walton O. Schalick, III, MD, PhD

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Schalick aims to understand the competing bureaucratic meanings of ‘quality of life’ with respect to children with disabilities in France, Germany, the UK and the US from 1802 to 1970. It is recognized that disability entered early in the health matrix. The history of QOL of children with disabilities in these countries is found in the health matrix or medical gaze, which focuses on regulation and medical solutions. Schalick visualized this history by showing a large collection of

archival sources and highlights the bureaucratic assessments of QOL of children with disabilities. A great deal of intervention for disabled bodies takes place in the 1830s in France and the use of 'play' is tested in Maison de la Mamasoin. Play appeared to alter the lived experience of children with disabilities and the method was later used in hospitals for adults. Lived experiences begin to increase in the UK, Germany and US.

Keywords: QOL, bureaucratic meanings, children with disabilities, medical gaze.

3. The impact of social capital on quality of life for elderly deaf persons

Joachim Gerich

Department of Sociology, Johannes Kepler University Linz, Austria

Gerich pointed out that a larger social network is significantly associated with higher quality of life for elderly deaf persons. This is highly related to the size of the network. The deaf network size is especially important for the QOL for elder deaf persons with low personal resources. During the discussion Gerich pointed out that deaf people often have better relations to hearing or deaf persons outside of the family environment. This is due to difficult relationships with people in the family because of the disability. Deaf people better relate to people in their network of deaf people and as such the network expands. The research subjects of this study were all members of the deaf community which could have led to biased results. Also the members of the network were retired which provides them with time to network, other than younger deaf people. Finally, the question of whether all the research subjects were born deaf or not was discussed. The research group appeared to be a mix of people who were born deaf and those who were not born deaf. Further research needs to point out what the differences in importance of social capital on QOL are from these different points of view.

Keywords: social capital, deaf persons, QOL

Concurrent sessions II

Friday, December 3 from 14.45 - 15.45 hrs

Session C1. How does disability experience affect quality of life?

1. Existential wellbeing and quality of life

Dorien Veltens and Axel Liégeois

Faculty of Theology, Catholic University of Leuven, Belgium

The presenter explained the concept of existential well-being by giving examples of questions such as 'Who am I?', 'Whose am I?', and 'What am I doing here?'. This type of well-being is influenced by spirituality and sometimes expressed in religious activities. Spirituality is a unifying experience. It belongs to everyone's daily reality and determines existential questions and answers. The presenter argued that no attention is paid to existential or spiritual well-being as an essential dimension of quality of life because the theory of quality of life is originated in the context of logical and positive sciences. As well, spirituality is often mentioned as an element of emotional and social well-being. The presenter stated that both objective and subjective information needs to be included to obtain a clear vision of quality of life. The presenter argued that the dimension of spirituality needs to be included in conceptualizing quality of life. In an example she described the life of Mother Teresa, who would not have been who she was without spirituality. As well she argued that in research on quality of life in persons with intellectual disabilities the spiritual dimension needs to be included.

The presenter described Fitchett's (2002) seven dimensions of spiritual life: belief and meaning, vocation and obligation, experience and emotion, courage and growth, ritual and practice, community, authority and guidance. Spirituality offers ways for understanding, motivating and finding meaning in life, is a way of coping and has an impact on the prevention and recovery of illness. The presenter claimed that spirituality is present in all people and does not depend on intellectual abilities. She described existential accompaniment as an empowering companionship between an existential companion and a person in his or her search for meaning in life that can be used in supporting people with intellectual disabilities. Near the end of the presentation she gave the following quote: 'We are not human beings having a spiritual experience, we are spiritual beings having a human experience'.

In the discussion an objection was made against interpreting the spirituality of Mother Teresa. As well, it was questioned what would be gained by including spirituality in quality of life, as it is hard to frame. The presenter argued that spirituality should not be neglected. She added the importance for people with disabilities to be meaningful to others and to have a valued role. The importance of spirituality for people with disabilities has been widely acknowledged.

Keywords: existential well-being, intellectual disabilities, quality of life

2. A qualitative study on physically disabled people and sexuality issues with personal assistance services.

Julia Bahner

Department of Social Work, University of Gothenburg, Sweden, PhD programme.

The presenter studied the experiences of people with physical disabilities with personal assistance, identity issues and societal attitudes within the context of sexuality using a contextual social constructionist approach. She applied the social model and administrative model of disability in conceptualizing disability and the sexual script theory and value hierarchy in conceptualizing sexuality. She touched on sexuality as a human right, asked questions such as what assistance is and should be available and reflected on how morals and values of personal assistants can be of influence.

Research on the living conditions of persons with disabilities from the viewpoint of sexuality issues is scarce. She found that persons with disabilities experience their sexuality as surrounded by barriers caused by societal and professional taboos. Judgmental attitudes cause experiences of ambivalence in using help. An ambivalent identity causes struggling for sexual rights. These factors relate to difficulties in forming sexuality and identity. The presenter discussed that persons with disabilities need to find ways for their own sexual practice and that it is important to work on issues of diversity in sexuality.

During the discussion attendees agreed on the importance of this topic. As well, it was agreed that sexuality is a very broad concept which encompasses many topics such as intimacy, relationships and reproduction. The presenter also posed the question whose quality of life is important to consider, the person with a disability who has certain needs, or the personal assistant that is required to perform certain tasks? It was concluded that this cannot be determined, but that perhaps some basic values could be established.

Keywords: sexuality, qualitative inquiry, barriers

3. Inequity in subjective well-being of people with chronic disabilities in 21 European countries

Cretien van Campen¹, Marc van Santvoort²

¹ Netherlands Institute for Social Research / SCP, The Hague, The Netherlands

² Bureau Onderzoek en Analyse, Amersfoort, The Netherlands

The presenter used quantitative data from a large European study in reporting on differences in subjective well-being between people with and without disabilities. He demonstrated that the gap in well-being between people with and without disabilities is different in various European countries. In particular, this gap is larger in Eastern European countries compared to Western Europe. The presenter used a model for explaining subjective well-being with the following elements: socio-demographics, participation, disability, satisfying life, personal competences and emotional well-being. The main determinants of the inequities in emotional well-being between people with and without disabilities were caused by personal competences and not by disability status. The presenter argued that the main determinants of gaps in subjective well-being can be applied in national policies. For example, vitality can be stimulated by programs for healthy exercising, supportive relationships by programs for social cohesion and optimism and self-esteem by programs for mental capacity.

In the discussion it was mentioned that the number of people who identify as having a disability is different among countries. The presenter explained that only differences in subjective well-being within countries were analyzed, not yet the differences between countries.

Keywords: subjective well-being, international comparison, quantitative research

Session C2. How does disability experience affect quality of life?

1. Trends in employment of people with disabilities in The Netherlands

Carla G.L. van Deursen, Anneke M. van der Giezen

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In her presentation, Anneke M. van der Giezen sketched the position of people with disabilities in the labour market. The policy goal of current social security schemes is to enhance participation in work for all disabled or chronically ill persons in an inclusive labour market. The aim of the study of the UWV is to evaluate the outcomes of this policy. Therefore they monitor the work status and trends in the work status of all recipients of disability benefits and all applicants who failed to qualify for disability benefits in The Netherlands. The results of their study are that between 2007 and 2008 the percentage of working partially incapacitated persons rose, but dropped again in 2009. Probable cause of the drop is the economic crisis. In general 50 % of people with a disability is working. An important conclusion is that people with disabilities who already had a contract participate more in the labour market than people who were unemployed before or just worked as flex-workers. The drop in the percentage of working clients in 2009 is higher compared to the drop in total employment. This suggests that the economic crisis had a higher impact on participation in work of partially incapacitated persons than on the rest of the work force. The results of this study will be published on this website: <http://www.uwv.nl/overuwv/kennis-publicaties/kennis/monitoren.aspx>

Keywords: employment, participation, development

2. Participation with Acquired Brain Injury in Contemporary Society: 'You have to learn how to deal'

Annette Hendrikx, Karen Schipper, Linda Dauwerse, Veronique Willems and Tineke Abma. VUMC, EMGO+ institute for health and care research, Dept Medical Humanities, Amsterdam programma Autonomie en Participatie in chronische zorg

The aim of this presentation is to show that social and societal participation for people with an Acquired Brain Injury (ABI) depends partly on their personal power to recover and adjust to society, and partly on the facilitating and constraining factors of our contemporary society. In the study the researchers examined the disabilities and the specific needs of persons with Acquired Brain Injury (ABI) concerning their societal and social participation. Their aim was to create a model of participation which reflects the experiences of people with an ABI. Furthermore the perspective of the patient has a central role in this project. The findings demonstrate that both personal and environmental factors and their interaction influence how and to what extent people with ABI experienced their disabilities. The disability derives its meaning from the environment, but how to deal with it in the environment, also depends on personal characteristics. Factors that play an important role are include resilience, will power, creativity and refusing to be a victim. In spite of various problems people with AIB are able to hold on to their identity and future wishes. They show resilience and develop individual power to find a meaningful way of life in our complex society. As a conclusion, a disability studies' perspective on people with ABI means having an eye for the environment/society combined with the psychological perspective of resilience. Participation of people with ABI in our contemporary society requires the power for being oneself and contributing meaningfully to our society as well as an enabling environment that creates space for people with ABI. In the discussion after the presentation the audience asked whether there are any differences between their model and the model of the ICF. Annette Hendriks answered that there are many similarities, but that there are certain differences. Their model focuses more on interaction, communication and dynamics. Furthermore the researchers considered it important that the model is formed by people's experiences. Another question addressed how the sample of informants was compiled and whether there were differences in the sort of brain injuries people suffered from. Annette Hendriks replied that the severity of the injury did not shape people's participation. Personal factors were more important. One person in the audience wanted to know how it felt to live with an ABI and to participate. Annette Hendriks explained that for people with an ABI it is important to participate and to be able to give. Further it is important for them to find their own usefulness. People with ABI often experience a of lack of understanding, they have problems with the invisibility of the injury and are often either under- or overestimated. A rapport in which all the results will be discussed will soon be published.

Keywords: participation, resilience, Acquired Brain Injury (AIB)

3. Happy to be taking part? Predicting the relationship between social participation and quality of live.

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The presentation discussed research carried out among people with learning disabilities or chronic psychiatric problems, living independently in de south-west region of the Netherlands. The aim of the study is to provide insight into the relation between participation and happiness. The main outcome of the calculations is that participation in society is not the most important condition for happiness of people with this kind of disabilities. In addition to their own attitude to life, it is their satisfaction within a number of domains of life treated in the model as determinants of participation which determines respondents' happiness. A conclusion that can be derived from these results is that there are only limited possibilities for promoting the participation of people with these disabilities or chronic psychiatric problems. Furthermore the outcomes suggest that increasing their participation will not necessarily contribute to their happiness. Questions that arose addressed the difference in importance between regular work and daily activities. Rick Kwekkeboom stated that this difference is very important and some people prefer to do daily

activities instead of regular work. Somebody added that it might be important to train people with learning disabilities as researchers as in his opinion people with learning disabilities would be more honest when among each other. Rick Kwekkeboom agreed that the use of 'ervaringskennis en ervaringsdeskundigheid' (the experiences of people with a disability) should be prominent in research. Another point that was discussed centered on the moral implications of Kwekkeboom's research. Society considers it important that people with disabilities participate, but what if they do not want to. Which consequences would that have? Rick Kwekkeboom states that it is important that people have a feeling of security and protection. Furthermore it is important to take the public opinion and attitudes of people into consideration when talking about participation and happiness.

Keywords: social participation, quality of life, happiness

Session D. Multi Cultural Perspectives on Quality of Life.

1. Quality of Life, Intellectual Disability and the Erasure of Cultural Differences

Frank A. Renders

KULeuven, Fac. of Social Sciences, Anthropology, Belgium

During his paper presentation Renders tries to explain that cultural differences are erased differently in the West than in the East. He uses the Indian traditions as an example. He argues that a cross-cultural perspective needs to be constructed that take the differences between cultural differences as its epistemological-methodological starting point. The West and East originally have a different kind of logic when it comes to knowledge: theoretical knowledge (hegemonic system) and performative knowledge. He argues that theoretical knowledge can be transformed by performative knowledge into 'renewed' hegemonic knowledge. This is the anthropological perspective on the way knowledge is acquired about quality of life in a residential institution for people with intellectual disabilities in the West (Belgium, The Netherlands). When one looks at the critical perspective on the way cultural differences are portrayed by employing 'intellectual disability' as a conceptual lens, Renders asks how 'cultural differences' of intellectual disabilities are shown in anthropological descriptions. The meaning of a traditional understanding of intellectual disability "Mundh Bhuddi" is reduced into an enumeration of external features that are mutually comparable, and are beholden as units that are structurally not different. The meaning of Mundh Bhuddi becomes less clear as it is not a universal understanding and is similarized to Western approaches. It is as if Belgium and India are the same in their difference. This example illustrates how 'cultural' difference is erased in anthropological descriptions of non-western cultures. Renders concludes that there is an absence of a conceptual framework in the social sciences and humanities to understand what these words mean from an Indian traditional perspective. Though, an Indian female professor from the public emphasizes that the West does not have a clue about Indian traditional understandings. Western knowledge does dominate knowledge about Intellectual knowledge in India, but less when it comes to traditional perspectives.

Keywords: intellectual disability, cultural differences, anthropology

2. Quality of life in Thai perspective

Silatham Sermittirong, Raj Pracha Samasai Institute,

Department of Disease Control, Ministry of Public Health, Thailand

During her presentation Sermirittirong outlines the outcomes of a study undertaken in Thailand in 2008 evaluating the QOL of Thai people in the whole country. For this study, 42 indicators based on Basic Minimum Needs were defined. The indicators were grouped in six categories, including health, housing, education, income, Thai values and participation in community activities. The numbers of indicators analyzed were different for every category, health included thirteen indicators, housing eight, education seven, income three and Thai value six. Out of all the 42 indicators, 20 indicators were achieved and 22 were not. In her presentation Sermirittirong showed that the Thai people assessed to be content about these indicators for almost 100%. Clean consuming water for example, reached a 95% which means that the indicator was almost achieved. Some people attending her presentation were critical about the approach and methods used to evaluate the QOL of Thai people. Some numbers seemed unrealistic according to some listeners and Sermirittirong emphasized the community-based approach taken to reach all Thai citizens. She also noted that people without basic living standards (homeless people) were not included. She furthermore highlights that it is remarkable that most achieved indicators belong to health and education aspects. The indicators that were achieved less are related to the performance of household members in taking care of the elderly and people with a disability. This is a notable result because the Thai values evolve around taking care of family members and respect for the elderly.

Keywords: Thai people, QOL, indicators

3. Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in South-East Nepal

Corline Brouwers*, Wim H. van Brakel*, Huib Cornielje***, Paras Pokhrel****, Krishna P. Dhakal**, Nandlal Banstola**

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During her presentations, Brouwers highlighted the results from her study amongst people with leprosy-related disabilities (PLRD) and their perspective on QOL. The results show that the participation and activity levels of people affected by leprosy were worse than those of the general population. She notes that PLRD are deprived of educational and employment opportunities. According to family, education is not important for PLRD which results in less job opportunities due to lack of education and physical restrictions. As such, they face disadvantage in income generation and are economically dependent on family. This leads to lack of availability of services and therefore lower awareness amongst the community. Perceived stigma and lack of awareness of the society about the psychiatric hazards of leprosy related disabilities result in low physical and psychological domain. The lack of awareness of the society also impacts the spatial and social environment of PLRD as no modifications of transport and facilities are made. The PLRD and the family face discrimination and the PLRD is sometimes ostracized by the family. People with DGII cases lower scores on psychological domain, they have no 'normal' working and social life and their bodily appearance is seldom accepted. The level of the visibility of the disease plays a large role in the psychological domain. The study points out that the QOL of females is lower, probably due to the dominant Maithilli culture. Women carry the responsibility for the household and health of their families, while suffering the most from social dependency and feelings of inferiority. Those women are twice as prone to divorce, separation and violence because of their disease.

Especially the DGII affected women are an important target for future interventions. The study pointed out that they face several disadvantages simultaneously (difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services provided by male service providers). It is not or hardly possible to use the study method for other disabilities, because of the strong characteristics of leprosy and cultural differences.

Keywords: Leprosy-related disabilities, stigma, South-East Nepal

Concurrent session III

Friday, December 3 from 16.15 - 17.15 hrs

Session A. To be or not to be

1. Beyond vocational rehabilitation as skills training: return-to-work as an identity issue

Lineke van Hal, Agnes Meershoek, Angelique de Rijk, Frans Nijhuis
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Labour participation is increasingly considered a vital aspect of taking part in society. To support people with a work disability in the process of returning-to-work, vocational rehabilitation programs are called into being. In these programs, much attention is paid to the skills that clients should develop in order to return to work. The norm of these programs is 'being healthy' and 'to be employed'.

Van Hal argues that vocational rehabilitation is more than the acquisition of skills. Further attention should be paid to clients' processes of identity work during vocational rehabilitation programs.

Labour participation implies new relationships and challenging one's identity. Therefore this research is based upon life story interviews and being analysed based on principles of grounded theory and typologies of (illness) narratives. The analyses focussed upon the relation between the body, self and society and their relation towards past, present and future. This reflects their identity in the workplace, defined as the dynamic and contextualised process of identity construction.

These processes of work identity constitute different narratives regarding return-to-work. Based on the performed work identity of people with a work disability, Van Hal presents an analytical division made between 'reparative', 'integrative', and 'pending' narratives. The performed identity work in these narratives is linked with the way in which the narrators relate themselves to return-to-work.

The integrative process of identity work is integrating different aspects of work: contextualisation, formulating of new perspectives, learning process and reinterpretation of the past. The pending process of identity work argues that identity is an explicitly under construction, an search for a new base in life, vital question of how to live and to come to terms with other life problems. Processes of identity work could be an important starting point for refining vocational rehabilitation support.

Van Hal argues that this typology can make vocational rehabilitation professionals more sensitive to processes of identity work of people with a work disability, and therefore support more inclusive vocational rehabilitation. Based on the results, she recommends further exploration regarding the different ways in which processes of identity work could be used in practice and its possible consequences.

Keywords: Labour participation, identity, inclusion

2. Being an entrepreneur, having an impairment.

M.L. (Mariët) Veen, MSc, Dr. P.D. (Peter) Groote, Dr. S. (Sierdjan) Koster

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People live in, feel with and encounter the world through their bodies. Moreover, it is a part of the self that is visible to others. Therefore, the body(-image) is an essential part of someone's self- and social identity. Since disability can be defined as a difficulty in functioning, experienced by persons with a *health condition* (which, in this research, affects the body), there must also be a relation between disability and identity. However, even though the disability is incorporated into the self, a person is not solely his or her impaired body.

Still, people are often socially defined exclusively by their disabled bodies. One context where this happens is the labour market. One way to (partly) circumvent that is by becoming self-employed.

Mariët Veen aims to explore the importance of the 'disability identity' for entrepreneurs with disabilities. Which one of their identities is more important, the disability identity or the entrepreneurial identity? What influence do these identities have on each other? And can being an entrepreneur help in not just being their impairments?

To answer these questions, here were conducted 33 in-depth interviews with self-employed people with disabilities. The respondents indicated that they certainly have a 'disability identity' but almost all respondents say that their disabilities are only a matter of secondary importance. More important for them are their distinct entrepreneurial identities. Even though some respondents state that their disability has shaped their entrepreneurial self, the relationship also exists the other way around. By being an entrepreneur, you can prove yourself as also existing outside or without the disability, as being more than just somebody who is disabled. That is why they also think it important to present themselves as entrepreneurs, and not as someone with a disability. Most of the respondents are 'Entrepreneurs with disabilities', and not 'Disabled Entrepreneurs'. As mentioned in the title of this presentation.

Keywords: labour participation, identity, inclusion

3. "Definitions of Disability and its implications"

Dr. Brigitte A.G. van Lierop

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Many definitions exist around disability. Much is unknown about the impact of the different definitions on data gathering, research and policy development concerning the participation of persons with a disability. Brigitte van Lierop focuses on the different definitions and their possible implications on the participation of persons with a disability and therewith on the impact of the use of definitions on data gathering, research and policy development.

Van Lierop argues that there isn't one single definition of disability. She suggests that we must no longer consider which definition will do best. Instead we should focus upon more important issues of participation. For example how Liza Waddington recently published about indicators for disability benefits and how the Washington group doesn't research whether one has a disability but focuses on what one is able to perform.

Van Lierop argues that one should consider what the data obtained by using definitions is worth. Does it really tell you something about participation or about quality of life? One should gather data and define these by focussing on policy development that really concerns the participation of persons with a disability. Therefore definitions around disability should benefit this kind of policy development. Van Lierop argues that we should really consider the qualities of participation. By who and by which is this quality being defined? She pleads for a holistic approach of researching the obstacles of participation.

Van Lierop pleads for a change. Don't aim at finding the label and by doing that finding the solution for a person with a disability. She prefers to look in a holistic way. What does one need to participate? Considering this she pleads for providing tools to let professionals in policy making or in the field of labour activity think this way also.

Keywords: definitions, participation, policy development

Session C. How does disability experience affect quality of life?

1. Dance education for children with special needs: kinaesthetic empathy and mirroring techniques.

Hermans, C.

1. Research Institute for History and Culture (OGC), Faculty of Humanities, Utrecht University
2. Lectoraat Kunsteducatie, School for the Arts, Amsterdam

Hermans' talk continues the debate over subjective versus objective knowledge into the realm of therapies for autistic, deaf, and ADHD children. She asks: is moving a way of thinking? Is sensation a form of thought? She uses what she calls kinaesthetic empathy and mirroring techniques in order to engage these children. She begins her argument by referencing a recent video called, "In my language," made by an autistic woman, Amanda Bagg, that recently blew up on YouTube. This video challenges what we accept as traditional knowledge production through the videographer's visual model of a sensory/perception hierarchy that spans from the deeply embodied to the abstraction of language (words). (Amanda spends most of her time in the comfortable lower levels.)

Hermans extends Amanda's ideas into the theoretical realm by comparing it to Erwin Straus' distinction between sensation and perception. In this model, sensation and perception are posed as the different modalities, comparable to phenomenology and psychology, i.e., subjective and objective knowledge—with the latter the privileged domain. Sensations—things felt in the body—are not knowledge, while those perceived (by the mind) are. But Hermans claims that her experience working with children, and as echoed by the video, argues that embodied knowledge is valid in its own right. Here she follows Merleau-Ponty's work that says that sensations are already charged with meaning. Sensations and perceptions can't happen separately, they are one substance with different attributes, which all belong to the body. That is the instrument through which all these things are mediated. In this way, she rejects the Cartesian split between mind and body. Her support of dance therapy and other embodied forms of knowing oneself and the world gives proof of her ideas.

Key words: dance, sensation, perception, phenomenology

2. Applying quality of life assessment in a therapeutic intervention for adults with developmental disabilities

Miranda D'Amico, PhD. and Stephen Snow, PhD.

Centre for the Arts in Human Development, Concordia University, Montréal, Québec, Canada

The center uses dance/ movement, art, and drama, for development for people with intellectual disabilities. The way they use QOL assessment is to evaluate the degree to which the person enjoys the important possibilities in his or her life. They use a QOL questionnaire during the candidate intake process. It includes fifteen-minute interviews with written verbatim answers. Some sample questions include: what are you good at? What do you think about yourself? What are your favorite things to do? Who decides what you do?

Choice is a really important consideration in QOL for people with developmental disabilities. They use a self-esteem inventory to determine if the individual has opportunities in her life for self-determination? Once at the center, they work with the clients for three years, and at the end of this period they reassess what kind of voice they have then. Have they gained agency? Are they doing things and creating goals for themselves based on their own choice?

This work is about tracking practical improvements in the individual's sense of belonging, choice, esteem, listening skills, turn-taking abilities, and so forth. Teaching individuals to understand the "self" and others, developing independence and empathy and making it more pleasant for group work all around, is the objective. Thus, the relationship between physical movement and embodied self expression and the ability to make independent choices and overall independence are connected to larger questions of empowerment and quality of life. The success of the program is evidenced in the extremely low drop out rate.

Key words: dance, choice, self-esteem

3. Ohrenblicke – making oneself heard by making radio as a leisure activity of blind people

Siegfried H. X. Saerberg

First audio snippet, which Saerberg translates from German: Fast computerized voices talking, male and female—anthropomorphized with the clapping sound of the cane of the blind person integrated into the music.

This is an example of a radio program that a consortium of agencies, an EU initiative, in Salzburg, Nurnberg, Cologne, and Utrecht help make possible by providing resources and education to the blind to make their own radio programming. Saerberg explains that the blind are long time listeners to the radio, which he describes as a link to a world. The participants in this program all have a biography of listening to the radio. But this is about making radio (and doing it without assistance once they receive instruction) that reflects their own perspective on culture. The program provides technical training and equipment, including assistive devices modifying typical audio technology. They also conduct workshops that teach people how to do journalism, conduct interviews, etc. The blind participants tell of their own perspectives on life into these programs.

Second audio snippet: A computerized voice overwritten by a travelogue. (again, translated into English by the presenter.) Train sounds discussing London underground. Cable car in San Francisco: the clanging bell. The experience is portrayed acoustically and narratively. Indian rickshaw experience, with beeping horns, putting motor, talking crowd. A richly layered audio travelogue.

Saerberg argues that, beyond basic access to education, employment, and physical space, quality of life is about meaningful experiences. Something you do on your own that fulfills you. To make a radio show on your own is to do something "fantastic." His approach claims that you can't divide life between leisure and occupational activities. In part because, though it starts as a leisure

activity, many of the blind radio producers later want to find employment at radio stations. Saerberg also argues that quality of life is not always individualistic. Because radio inherently must reach out to people, so the programs must convey common means of communication, values, and knowledge. The collective effort also means that people get to work together with each other and local radio stations. It would be no fun if they do it on their own. Thus, quality of life is about collaboration, not just creative expression. Participants gain knowledge and new experiences, meaning this kind of pleasure needs to be integrated in measures of QOL.

Key words: radio, participation, leisure

Session D: Multi Cultural Perspectives on Quality of Life

1. Diversity and Quality of Life of Persons with Disabilities (PwD) in Indonesia

Mimi M.Lusli

PhD student at VU University/ Director of Mimi Institute

The presenter explained the importance of the motto 'Unity in diversity' in Indonesia. She demonstrated however that the percentage of students with disabilities in higher education in Indonesia is very low. Only 0.04 % of people with disabilities in Indonesia have a Bachelor's degree and this includes the presenter. In Jakarta, in five senior high schools, only six children with disabilities are educated. Among the fourteen universities in Jakarta, only twenty-four students with disabilities are registered. However, there are many disability policies in Indonesia. For example there is a quota of 1% in employment of persons with disabilities. As well, the Indonesian government signed the UN Convention on the Rights of Persons with Disabilities in 2007. However, the policies have not been implemented well and unsupportive cultures, attitudes, values and beliefs are prevalent.

The presenter argued that as a country, Indonesia needs to put disability in the process of democratization. She stated that persons with disabilities and disabled people's organizations will never stop fighting to enjoy their human rights. The presenter also shared some of her personal experiences with being blind and with education. She also mentioned important differences between the various Indonesian islands.

Keywords: multicultural perspectives, education, policy

3. Becoming metaphors – on the interrelationship between 19th Century psychiatric photography and the shaping of identities.

Bregt G. Lameris (Ph.D)

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This presentation addressed the production of mental illness in the 19th century by psychiatric photography and its influence on the meaning of mental illness. An image made in 1858 by Hugh W. Diamond called 'Suicidal melancholy' is an example of how a woman with mental illness was not longer presented as a person but as a disease. This process of scientification was described by Rosenberg (2002) in 'The tyranny of diagnosis'. In this period in the nineteenth century a specificity revolution occurred, and instruments of precision such as thermometers and microscopes started to be used. The presenter would like to add photography since it was

intensively used as a scientific tool as well. In the Lancet it was mentioned to be 'an instrument of objectivity'.

Three different techniques in psychiatric photography in this time period were instantaneous photography, posed photography and composite portraiture. This last technique was established by Galton but did not work as well as was envisioned. Taylor (1885) wrote in a counteraction against Galton that 'not all men look bad the same way'. The presenter also explained that posed photography seems to contradict objectivity. However, in that time this was not considered to be the case.

In the discussion it was mentioned that the 'Dolhuis' museum in Haarlem, the Netherlands, has a collection of psychiatric photographs from the discussed time period. Extensive research is needed on this collection. It was also remarked that in addition to photographs, moving images were used as well. In the beginning of the twentieth century pictures and images were recorded on the 'normal' development of children which enabled juxtaposing children with and without disabilities. The presenter added that in the nineteenth century, psychiatrists also asked for a premorbid picture of the patient. In conclusion, the impact of stigmatization on the dominant identity of individuals was discussed. Another example provided of persons being transformed into cases, was the leper colony on Robben island in South-Africa, where persons' names were no longer used upon entrance and persons were assigned a number.

Keywords: disability history, photography, mental illness

Cultural programme

"Signed poetry and the power of visual communication"

Presentation of signed film poetry by Anja Hiddinga

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Concurrent session IV

Saturday, December 4 from 11.00 - 12.00 hrs

Session A. To be or not to be

1. 'Being at work' - how to include people with disabilities in regular work organizations-

Frans Nijhuis, Fred Zijlstra, Henny Mulders

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A variety of supportive measures is available to people with disabilities to enhance their labour market position, as compensation for their obvious disadvantages in competing with other job seekers. Considerable financial and professional efforts did not result in substantial increase of work participation of people with disabilities. It seems that more is needed to establish a more inclusive labour market.

Work organizations will have to develop an alternative approach: fitting the job to the person.

Work redesign is necessary to offer jobs and working conditions that fit the individual characteristics of people with disabilities. Henny Mulders claims that work organizations are thinking exclusive and as a result work is not designed for people with disabilities. But times are changing. The social security system in The Netherlands no longer offers financial support. It's shifted to providing a contribution towards stimulating participation. People with a disability must be able to do some sort of partial work in order to earn money. This means the labour market has to become inclusive.

In The Netherlands 220.000 youngsters have a wajong-uitkering, which means they can't perform a 'standard' job. Employers often misunderstand disabled persons. People with disabilities between 18 and 27 years of age mainly have developmental and psychological disorders. They often prefer a type of job that involves for elementary tasks and a staff that is willing to provide low skills activities.

Henny Mulders presents the developed method 'participative work redesign' to support work organizations in their efforts to become more inclusive. This method is being applied in a field experiment in cooperation with a general hospital, the Slotervaart ziekenhuis in Amsterdam. It focuses upon the demand site approach of rehabilitation. It's orientating toward empowerment and coaching. People with disabilities are being recruited, selected, trained en incorporated into a highly adaptive, inclusive organization. This is accomplished by reconsidering the task that has to be done at the hospital wards. The qualified staff is no longer doing the daily routine, this is done by the wajongers, so the qualified staff are focusing on their qualified job. Nine steps are designed to make this happen, which includes a successful matching of candidates, a job coach / mentor for the candidate and a willing line manager. The result: the hospital creates a regular position for a candidate with a Wajong, funded by all employers and a salary paid by the hospital.

Keywords: Labour participation - inclusive - participation

2. Dynamic and functional assessment for a developmental and inclusive perspective

Jo Lebeer, Petri Partanen, Krisztina Bohacs, Gunvor Sonnesyn, G., Adelinda A. Candeias, Luisa Grácio, Karmen Demeter, Thomas Alexander & Lorna Dawson

University of Antwerp, coordinator of Daffodil Project, INCENA (Inclusion & Enablement), Faculty of Medicine, ELIZA (Primary & Interdisciplinary Care)

Jo Lebeer presents a research study that questions how functional and learning assessment systems facilitate or inhibit participation of children with developmental difficulties in (inclusive) education.

The results reveal that, in Europe, static standardized psychometric tests of intellectual, behaviour and language functioning is still dominating. One recognizes the utility of functional assessment in obtaining disability benefits (financial, special education resources, recognition and relief of uncertainty and guilt). But there was great dissatisfaction with the mainly negative outlook of reports and deficiency labelling. This often leads to a devaluation of the learning capacities of a person with impairments and reinforces their disability situation.

Lebeer concludes that functional assessment is appropriate if it is not oriented only at diagnosing current level of functioning but also at proximal, potential and future functioning. Thus, functional assessment in itself is not good or bad. It may be an obstacle to inclusive education when it is merely oriented at stating deficiencies. And because of this creates a negative belief system or cause teachers to make "inclusion" conditional to test results. Formative assessment (assessing a child's potential in a dynamic way) is considered more facilitating towards inclusive education because it gives information on what could be done to help the child function better. However, interpretation, communication and implementation of assessments are considered crucial. Lebeer claims it's necessary to make assessment reports more useful to adapt educational intervention to the child's specific needs and to coach the teams that work with the child. Professionals in assessment need to be trained to change their minds and practices. The Guidelines for Dynamic Functional and Inclusive Assessment can be a tool for this conceptual change.

How can teachers cope with all the special needs of their pupils? The audience argues it can't be the responsible of the teacher or the employer. In order to become inclusive a total reorganization of the school or work organization is needed. Lebeer argues that characteristics of a good school

are a community where all people are involved. Volunteers and teachers are working together to provide all kinds of educational intervention to the child's specific needs. The audience agrees that this has not yet political priority. There still is a huge gap between the UN-convention and integrating this into proper policy.

One asks for more research to be done by a cooperative scientific and the professional field. More teachers or employers should be challenged to question on a professional scientific level what they are doing in their daily routine. Because 'what means evidence based if you don't have the evidence'.

Keywords: Education, inclusive, assesment

Session B. What distinguishes disability studies?

1. 'Conceptual comparison of methodological issues in assessing disabled functioning and capabilities'

Jean-François Trani and Federica Di Marcantonio

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University of Rome "La Sapienza", Rome, Italy

After explaining the medical and social model of disability the presenters introduced the ICF model of the World Health Organization which considers both impairments and social factors and makes comparisons of studies in different countries possible. Next, the presenters discussed the different limitations of these models. The social model poses a problem for public policy since people with disabilities still need support after all barriers are removed. The ICF model is still based on giving quantifications for medical professions. Also, it does not consider the interaction between individual and society in its definition of disability. The classification is also problematic because it does not take cultural factors into account.

Additionally, the presenters explored the capability approach of Amartya Sen which shifts the focus from specificities of disabling to freedom of choice and individual agency. In this framework disability is conceptualized as a lack of capability, the ability to do or be something. It considers the possibilities of persons instead of what a person actually does. It goes beyond the medical and social model and focuses on reducing vulnerabilities and on policies to increase capabilities. The presenters argued that individual agency as in persons deciding on their own life, has been neglected in previous models.

The presenters state that in research, disability should be understood as deprivation of capabilities. They argued for an emphasis shift from how people function to what they would be or do if they had sufficient opportunities. Opportunities offered by environments should be assessed and the choices that people have. The researchers developed a questionnaire, a multidimensional screening tool to identify disabled people. It focuses on actual achievement, desired achievement and freedom of choice. They have data from the National Disability Survey Afghanistan and the Blind Capability Survey. The presenters mentioned as a weakness of their approach the fact that it does not take into account the exercise of capability in opposition to a passive operation.

In the discussion there was attention for the importance of qualitative measures and of cultural differences in for example individualistic and collectivistic societies. As well, it was commented that in the relationship between functioning and the individual capability set, the influence of the internalization of stigmatization and discrimination which causes people to believe they do not have certain opportunities should not be underestimated.

Keywords: models of disability, multi-cultural perspectives

2. The blind, the sixties and religious care

Paul van Trigt MA, PhD

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The presenter started with an introduction of the 'new disability history' as described by Longmore and Umansky and emphasized the importance of viewing disability as a socio-historical construction. He described how social welfare in the Netherlands in the twentieth century was characterized by charitable motives. Patronization has dominated in this field and blindness was considered a functional deficit. The presenter provided an example of 'Sonneheerdt', a Dutch religious institute for blind people. In the period of 1920 through 1960, 'Sonneheerdt' strived for normalization by paid work and supervised independence. The presenter posed that this example asks for 'a careful renewal of the regime of charity'. Between 1960 and 1980 the institutions were seen as obstruction to normalization. Also a Christian solidarity with the 'weaker' blind was recognizable.

Keywords: blindness, disability history

Session C. How does disability experience affect quality of life?

1. Act Normal: a personal account on common views on "normality" and "disability" and the essential need to belong and be different at the same time.

Thiandi M.A. Grooff

Thiandi Grooff is a twenty-year old student in Amsterdam, the Netherlands, which she believes is a very exclusionary country. She now attends Amsterdam University College and lives independently and is happy. As she puts it, this is normal for everyone so she is no exception. But, at the same time, as she is disabled, this is also a remarkable achievement.

She has always known she was special because of the reactions of the people around her. Until she was fourteen years old, she was considered to have severe learning disabilities and her parents had to struggle against the Dutch institutions to allow her to be educated with other kids. Her breakthrough came when she and her parents discovered facilitated communication, because of which she can show that she can think, and thus, is no longer considered mentally disabled. She feels others should have a right to this powerful tool.

She has written a book called *Doe Normaal* (Act Normal) to demonstrate that she has ordinary feelings even though her body is not normal. Her strange body predestines a lot. She wishes she could change her body. But she knows that is not possible. She can't change herself, but she can change the people around her to understand whom she is inside. She has succeeded already: people can change. For example, at Amsterdam University College they have accepted her. But, she asks, is that enough to change the discourse among the majority? She has doubts because the disabled in Holland are not visible enough. So the first stage is visibility.

Grooff notes that, in Nietzsche's view of the eye (perception) as the measure of how we understand if we belong in society, she is clearly an outsider. She recognizes the split between her body, which she can't control to function in a way that is acceptable as normal, and the normal way that she feels on the inside. She offers John Stuart Mill's conception of diversity as an alternative model for how community can be enriched. Something she feels is greatly lacking in Holland's attitudes towards the disabled.

Key words: normal, facilitated communication, acceptance

2. Towards a participatory culture: children or adult clients as co-researchers in a residential care institution for people with intellectual disabilities and significant behaviour problems

Dr. Xavier M.H. Moonen

University of Amsterdam, Amsterdam

People with learning, behavior, and psychiatric problems are more commonly institutionalized in the Netherlands. Yet, Moonen claims, that when people are referred to institutions, there is not consensus about what the diagnosis is or what their goals for progress are. He proposes that the paradigm of “conclusion” helps the care providers have the same vision of outcomes as the client. Working with clients, elicits their own definition of problems, their own questions, and the ways they want to develop themselves. This should be the starting point. He asks, why can't clients be their own researchers? Even people with intellectual disabilities could participate in the design of their own care. There are ethical questions, but there is a lot of room to explore the idea of clients as their own researchers. This way both client and therapists share the same vision of what the problem is, which should lead to better results.

Moonen described some projects that took place in facilities with children or young adults with mild intellectual problems and severe behavioral problems. They treated the clients as experts, assuming that they know best what should be altered in the institute. Their goal is to give them more control over their lives even in the institution. The project leaders don't have a goal in the research. They have the clients choose the relevant research questions, methodology, and analyze the data and work with the facilities manager to implement the results. They do provide tools to enable the clients to design the experiment, such as those for brainstorming, data collection, and data presentation. They try to use unconventional methods: letter, brochure, video, song. They also need tools for collaborating with management. This approach, Moonen claims, leads to better results, and the system runs more smoothly when the clients have agency in this process.

What does this kind of work do for the client's competencies and the competencies of the social workers? What are the treatment goals? And if the clients themselves set the goals, how does that affect what the goals are, whether they are attained, etc? This paradigm shift has the potential to affect the whole institute, as well as enable clients to gain confidence and coping skills.

Questions from the audience focused on two things. First, are there things that people with such mild intellectual disabilities can do better than traditional researchers? Do they have special insight? Moonen thinks so, and supported this with an account of valuable information gained about conflict management from talking with clients. When challenged about the morality of institutionalizing children at all, and whether the setting itself makes the kids “not normal,” he steadfastly stated that some do need to be institutionalized.

Key words: empowerment, research, institutions

3. Hearing ability and its association with psychosocial health & need for recovery after work in adults aged 18-70 years.

Sophia E. Kramer¹, Janneke Nachtegaal⁴, Cas Smits¹, S. Theo Goverts¹, Johannes R. Anema², Marieke Stam¹, Jan H. Smit³ Joost M. Festen¹

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Kramer presents the methodology and findings of her and her colleagues' medical research on the effects of hearing abilities in participation in wellbeing and work. The research project arose out of a concern that hearing loss has gone as an undetected factor that produces a cascade of negative productivity and quality of life effects. The study also looks at the relationship between hearing loss and distress, somatization, loneliness, depression, and anxiety. Especially as people get older, hearing loss becomes more common. At the same time, many are active in the work force and those with hearing loss will more often end up in a vulnerable position, for example, losing jobs, not always voluntarily. This is becoming an increasing problem in part because we're now in a more knowledge-based, rather than a manual-based, economy. Hearing is critical to the communication of knowledge. Hearing loss, thus leads, to productivity loss.

The author's approach is quite traditional demographic-functional since she argues that hearing loss is a real part of the work environment and concludes that it leads to loss of productivity. In studying impairment and work, they had to develop their own data about how hearing impairment affects workplace productivity and experience. They concluded that there are a lot of different things that need to be taken into account: the match between workplace environment, such as what kinds of jobs are performed, what are the spatial acoustics, supervisors and colleagues, schedule, and the auditory profile.

After the presentation, Lennard Davis from the audience asked whether there are researchers that themselves are hearing impaired involved in the study. Kramer answered that there is someone involved in consultative way. However, his larger point is, how does her presentation fit into disability studies? Disabled people are over studied already. That they are the objects of the medical research is what disability studies rejects and aims to redefine. So how does this research address a kind of empowerment discourse or disrupt the normal medicalized object that disability studies opposes? Kramer did not appear to understand the point nor really address his question.

Key words: hearing loss, productivity, auditory profile

Session D. Multi Cultural Perspectives on Quality of Life

1. "Making sure that this does not happen again": Women's leadership as an Actor in Special Olympics networking in Paraguay

Patrick Devlieger

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In his presentation Patrick Devlieger discussed a study of Special Olympics in four countries (Namibia, Paraguay, Uzbekistan, Thailand). By applying actor-network theory he especially focuses on aspects of women's leadership in Paraguay as only there women's leadership which has grown from the experience of being a mother of a child with mental disabilities has been very prominent. In his presentation experiences of three women are discussed. He argues that the women's leadership is based on disappointment with the current situation and the wish to improve the situation. Having a leading position means that the women can expand their friendships and help each other to move ahead in society. Devlieger concludes that women's leadership in Paraguay can be understood as based in the local and global social experience of Special Olympics, in the authenticity of the experience, and in the particularities of Paraguayan culture. After the presentation different questions arose, for example about the role of the government. Patrick Devlieger explained that especially the US government and the collaboration between the women and the local government played an important role. Furthermore in this collaboration the women used dynamic ways of profiling leadership. Another person in the audience wondered whether the Special Olympics had any spillover benefits and how the event was covered by the media. In Paraguay, in contrast to other countries, the media was very active. Sport journalists

pictured disabled people's emotions and the media was even able to move one athlete to the status of a national icon.

Keywords: actor-network theory, leadership, special olympics

2. Disability: Poverty and violence in Brazil

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Keywords: poverty, violence, Brazil

Disability, poverty and violence are central topics in Crispim Campos' presentation. He sketches the situation of people with a disability in Brazil. First of all he states that one third of the population in Latin America lives in poverty, which means people have to live with two dollars per day. Striking in Brazil is the extreme discrepancy between urban and rural areas. Furthermore a correlation between poverty and disability can be found. A study showed that in households with a disabled person there were many instances of violence in the form of neglect and physical abuse. In the subsequent discussion the audience asked whether there is a difference in meaning of disability whether it is acquired 'normally' or whether it is caused by violence. Crispim Campos replied that his research did not indicate a difference.

3. Getting to know you...: disabled people and the politics of friendship in Ecuador

Beatriz Miranda-Galarza
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Beatriz Miranda-Galarza started her presentation with a personal account of her family situation. When her father and grandmother died a lot of people came to their funeral. However, when her brother who has been labeled as intellectually disabled, died only the nuclear family came. Her other brother, also labeled as intellectually disabled, asked her whether people will come to his funeral. From this starting point Beatriz Miranda-Galarza talked about the notion of friendship and social inclusion among people with an intellectual disability. She argues that when exploring the intimate life of people with an intellectual disability and their families, inclusion seems to display a different narrative. Relationships, and specifically the politics of friendship, appear to be superficially considered in the discussion about building inclusive networks to improve the quality of life of those individuals. Beatriz Miranda-Galarza argues that intimacy and mutuality are the main tools for such a construction. "Getting to know" a disabled person could contribute to a better and profound understanding of what friendship means and the transcendence of that relationship.

Keywords: intellectual disability, friendship, Ecuador