

Conference Report

Disability Studies International Conference

'The Art of Belonging'

October 31st - November 2nd 2013, Amsterdam, the Netherlands



DISABILITY STUDIES

in Nederland

by Lieke van Heumen, MS; Karin van den Bosch, MS; and Lotte Werkema, MS

“Some of us aren’t meant to belong.

***Some of us have to turn the world upside down and shake the hell out of it
until we make our own place in it.”***

Elisabeth Lowell: Remember summer.

Welcoming remarks

From Thursday October 31st through Saturday November 2nd 2013 the Disability Studies international conference with the theme **‘The Art of Belonging’** took place in Amsterdam, the Netherlands. The conference was organized by Disability Studies in the Netherlands and the VU University Amsterdam. This was the second international Disability Studies conference in the Netherlands. In 2010, a successful first international Disability Studies conference took place in Amsterdam with the theme ‘Diversity in Quality of Life’. In this conference report you can find information about and impressions of the various events and presentations during the conference ‘The Art of Belonging’.

The theme of the conference had a focus that traversed the tensions between disability experience, the art of living and belonging. It is every person’s right to belong, but belonging is much more than a right. It is something people have to learn and develop throughout life, through their personal experiences and social participation. It is individuals with disabilities finding their places in life, without compromising themselves for the purpose of ‘fitting in’ and nondisabled people finding their places in the world of disability. Belonging is a state of mind, achieved through ongoing activity where shared spaces of interest and excitement are not only accessed, but also negotiated, and ultimately occupied. More than just being ‘at home,’ belonging requires overt, and sometimes political, action.

Thursday afternoon: IASSIDD Pre-conference workshops

In collaboration with the International Association for the Scientific Study of Intellectual and Developmental Disabilities two pre-conference workshops took place for interested attendees. The first workshop **‘Dementia and Age-Related Decline in People with Lifelong Disabilities’** was prepared by Matthew P. Janicki, PhD and Ronald Lucchino, PhD. Dr. Janicki works at the University of Illinois at Chicago and is the Co-Chair of the US National Task Group on Intellectual Disabilities and Dementia Practices. Dr Lucchino is affiliated with Utica College in New York and the Area Agency on Aging of Southwest Florida. This workshop consisted of six related high content lectures and mostly focused on aging of persons with intellectual disabilities. Eight people were present for the workshop and three of them worked with people with intellectual disabilities.

Dr. Janicki presented background information on dementia in persons with intellectual disabilities during the first part of the workshop. Alzheimer’s disease is considered one of the most frightening and

disabling diseases as people grow older. According to the WHO report on dementia the number of people with AD will continue to grow, particularly among the oldest old. People with Down syndrome are at a significant risk of developing Alzheimer's disease. Studies suggest that 50 to 60% of people with Down syndrome will be affected by dementia after age 60. The prevalence rate of dementia in persons over 60 years of age in the general population is about 5-6%. This rate is similar for people with other types of intellectual disabilities. People with intellectual disabilities and caregivers need additional supports if and when they are affected by dementia. A barrier this populations faces includes the lack of understanding and recognition of dementia in older adults with intellectual disabilities. Additionally, there is a lack of appropriate information, resources and services for this group. The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the USA has developed a report with policy and practice recommendations in supporting adults with intellectual disabilities affected by dementia.

A common element in most national dementia policies is to move away from support in large institutions to smaller, more individualized settings. An additional aim is to enable individuals with dementia to remain at home as long as possible. They are given as much control over their own supports as possible, while recognizing limitations due to cognitive impairments. Caregivers are supported in order to delay the move of individuals living with dementia to long-term care settings outside of the home. Dementia care planning should take into account the different stages of the disease. The supports needed are different in the early, mid and late stages of the disease. It is important for dementia policies and practices to be aware of the needs of minority groups, such as people with intellectual disabilities and groups who are at particular risk, like people with Down syndrome and people with traumatic brain injuries. Goals for the NTG are to create a national plan on dementia and intellectual disability, to identify a workable administrative screening instrument, to produce health/screening practice guidelines and to define best practices for community care.

During the discussion the question was raised whether it is better to adapt mainstream nursing homes so people with intellectual disabilities and dementia can be supported in these settings as well or to adapt settings for people with intellectual disabilities to better be prepared for supporting those who also develop dementia. The reality is that many nursing homes are unwilling to support people with intellectual disabilities. Persons with intellectual disabilities have lived different lives and have a set of unique experiences. Practice tells us that organizations for people with intellectual disabilities are preparing and adapting to support the larger number of people who also will develop dementia. Both mainstream aging services as well as intellectual disability services should learn from each other in order to most effectively support persons with dementia. It is of importance that all healthcare professionals learn about effective supports for persons with intellectual disabilities.

During part two of the workshop Dr. Lucchino addressed biological aging and health care disparities in persons with intellectual and developmental disabilities. His presentation described the vulnerability of the adult aging with intellectual and developmental disabilities. Without appropriate supports for age related changes the risk of these adults to live in a more restrictive environment increases. Dr. Lucchino explained the differences between age-related changes, age-associated changes and age-associated diseases. Age-related changes are part of the normal aging process and are experienced by all persons

growing older. Age-associated changes are changes that occur at a higher incidence in older individuals and are caused by neutral or negative genes and or a poor lifestyle, increasing the vulnerability for a loss of independence. These changes are not experienced by everyone. Age-associated changes are not part of the normal aging process but the result of an accumulation of negative lifestyle choices interacting with negative genes. Age-associated diseases are changes caused by negative genes and poor lifestyles leading to diseases that can reduce independence. These diseases can either be prevented or reduced with interventions.

During the third part of the lecture Matthew Janicki spoke in more detail on the characteristics of dementia in people aging with lifelong disabilities. The aim of the fourth part of the lecture by Ronald Lucchino was to increase awareness, knowledge and skills to reduce the high risk of hospital admission of older adults with intellectual disabilities. They are six times more likely to be admitted to the hospital than the general population. Dr. Janicki then spoke in more detail about the NTG practice guidelines for the evaluation and management of dementia in adults with intellectual disabilities. The workshop ended with a lecture by Dr. Lucchino on how medications may increase ACSC (ambulatory care sensitive conditions) by mimicking, masking, exacerbating or causing diseases in older adults with intellectual disabilities. It is critical that formal and informal caregivers are well informed about the effects of medications. In addition, it is of importance to inform health care practitioners about adverse drug reactions in older adults with intellectual disabilities, especially in people with Down syndrome or cerebral palsy.

The population of persons with intellectual disabilities is growing older with similar aging concerns as the general population. A critical area of concern for both populations is the increase in medication use and its negative effects on functioning. There is more awareness of this concern in the general population than in the population of people aging with intellectual disabilities. The increase in medication use by persons with intellectual disabilities is due to the increase in chronic co-morbid conditions. Early age related changes may also influence drug levels in the blood of adults with Down syndrome.

Rhonda Faragher, PhD and Nina Zina, PhD gave the second workshop **‘Quality of Life Applications in Education & Families: Challenges and Solutions’**. Dr. Faragher is the Head of the School and Senior Lecturer of the Faculty of Education at the Canberra Campus of the Australian Catholic University. Dr. Zuna is affiliated with the Meadows Centre for Preventing Educational Risk at the University of Texas at Austin, Department of Special Education, Austin, USA. Because of illness, Professor Roy Brown was not able to attend the workshop. Dr. Brown can be reached by email at royibrown@shaw.ca.

Dr. Rhonda Faragher became a researcher because of her daughter Ruth who was born in 1996 with Down syndrome. At that time, Dr. Faragher was a mathematics teacher. She was worried about the education of Ruth. In 1996 the knowledge about educating persons with intellectual and developmental disabilities was scarce. During the introduction on the topic of quality of life Dr. Faragher posed the question why education of individuals with intellectual and developmental disabilities is important. She stated that a life spent sitting on the beach doing nothing is not good for our quality of life. People need

to learn in order to improve their quality of life. Education improves social inclusion and provides personal fulfilment.

To experience quality of life we need to be able to make our own decisions, feel satisfied, be connected to other people and experience social inclusion. Our quality of life also depends on how others perceive us, whether we feel respected and enjoy the right to be the person we are. The concept of quality of life emerged over time. There are a number of commonly accepted ideas about this concept, namely that quality of life is social wellbeing enjoyed by people, communities and their society, is both objective and subjective and involves material wellbeing, health, productivity, intimacy, safety, community and emotional wellbeing. Furthermore, quality of life is experienced when a person's needs are met and when he or she has the opportunity to pursue and achieve major life goals.

For people with intellectual and developmental disabilities it is not important to 'fit in' in order to experience quality of life. They have the right to be as they are and it is important they gain control over their lives in order to experience quality of life.

The common usage of the quality of life concept in for example advertisements for a wide variety of products has caused for it to lose some of its power. In family and historical research the concept of quality of life is particularly important as the ideas about intellectual disabilities have changed during the past century.

Family quality of life is an important concept as successful children live in supportive, healthy family environments. During the workshop it was examined what family members with a relative with an intellectual and or developmental disability in 14 different countries stated about their family quality of life. These insights can help support these families. Furthermore, the workshop discussed how to use family quality of life based assessment in family support and interaction and explored application of quality of life principles in education. Quality of life and education in schools and universities is an area of research and practice which has remained largely unexplored. During the workshop the need for the implementation of such an approach was discussed and practical examples of how this approach may be applied were presented.

A case study of a boy with Down syndrome was discussed. The boy was really bored during mathematics lessons. His fellow students were learning the Pythagorean Theorem while he was playing childish games. The teacher found out that the boy was able to attend the same lessons as the other pupils, provided that some adaptations were made to the lessons. He was given an object that already had the right angle so he could replicate it. Because of this adjustment the boy was able to do the same exercises as the rest of the group.

Thursday night: opening Disability Studies conference 'The Art of Belonging'

Alice Schippers, the director of Disability Studies in the Netherlands, opened the Disability studies conference and welcomed all attendees. She stated that everyone probably already met the persons sitting to their left and right, hence provided all with the opportunity to take a moment to meet the persons sitting in front and behind oneself.

Soprano Andrea van Beek provided an artistic opening to the conference that was greeted with a standing ovation and had participants buzzing with excitement afterwards. She performed an emotional story about her eight year old son Jim who has severe multiple disabilities. In three pieces Andrea van Beek explored her relationship with Jim through a combination of poetry, singing and music. The performance created synergy between the different voices and made Jim an equal artist in the dialogue. Jim's voice was displayed with an audio recording on which he could be heard communicating by making an array of sounds. Bass clarinet player Gareth Davis added a layer of complexity to the mother and son duet. The performance created and recreated various different atmospheres, from peacefulness to chaos to excitement. Importantly, it valued the interaction of different forms of (non-standard) communication in creating the story about a disability experience.

After this performance Ruth Faragher, a young woman with Down Syndrome from Australia, welcomed the participants and invited all to dialogue and meaningful conversations during the course of the conference. Ruth stated she liked the relaxed performance by Andrea van Beek and that it is important to keep calm and enjoy the music.

Alice Schippers shared some information about the artwork by Bert Janssen exhibited at various locations in the conference hotel. The work 'True Colors' that is displayed on the cover of this report was chosen as the logo of the conference.

As part of the dynamic opening to the conference Jenny Goldschmidt, professor in human rights law at Utrecht University in the Netherlands, shared how deeply she was touched by the performance by Andrea van Beek. She felt it conveyed a sense of belonging that is difficult to express. She stated that as a deaf woman using cochlear implants it is difficult for her to determine whether she belongs to the deaf or hearing community. She explained that Disability Studies in the Netherlands aims to connect research to daily practice in order to improve the quality of life of persons with disabilities. This aim is reflected in the theme of the conference. She stated that belonging is much more than a right. In her view, belonging refers to learning and developing through life experiences and social participation. This consists of persons with disabilities not having to compromise in order to fit in with the nondisabled community and of able-bodied persons finding their place within the disability community. She demonstrated that defining belonging as right is problematic, because who should give one this right? Who should enforce it? She conceptualized belonging as being social and emotional in nature and stated that law is not the best instrument to develop this belonging. Law can give us the room to belong and the room not to belong, the right not to be forced to be part of a group we do not feel we belong to. Law can provide one with choices. Furthermore, she described belonging as the fight against exclusion. It is of importance that people are not excluded based on their identity. The dilemma at hand is how dominant culture can incorporate diverse views.

During the opening of the conference the emphasis on artistic expression as it relates to disability clearly honored 'Art' within the theme 'The Art of Belonging'. Furthermore, it kicked off reflection on what 'Belonging' means as it relates to the human experience and disability.

Thursday night: key note presentation by Dr. Ann Turnbull

The first keynote was presented by Dr. Ann Turnbull, distinguished professor at the University of Kansas in the United States. She started her presentation with a picture of a fork on the road. She stated that when we are presented with a fork in the road we can take the road that leads to inclusion and belonging or the road that leads to marginalization. Her presentation focused on what she and her husband, distinguished professor Rud Turnbull, learned about the inclusive road they travelled with their son Jay. Jay had extensive disabilities and died four and a half years ago at age 41. During the presentation Ann Turnbull discussed inclusive practices withstanding the test of time and the lessons Jay taught us while traveling the road towards belonging. Dr. Turnbull described the importance of a life span focus in this inclusive road. However, most attention exists for childhood rather than for adulthood. In describing the life Jay lived with the support from his family and friends Dr. Turnbull focused on his transition to adulthood during the early 1980s. During this time the common practice was to prepare young adults with significant disabilities to work in sheltered workshops. His parents rather wanted Jay to have a job coach so he would receive support to hold a regular job. Jay's transition to living in a group home proved to be problematic. He was unhappy and because of his behavioral outbursts he was expelled from the program. It was not the best program for Jay but the only one in the area. The program had no interest in accommodating Jay's needs. After a visit to Jay his then 10 year old sister stated: "Mom, you wouldn't want to live there. I don't want to live there. Why does Jay need to live there?" Jay's sister knew he was experiencing second class citizenship. This made his parents wonder what it would take for Jay to live the life he wanted, an enviable life as we want for ourselves and our family.

Ann Turnbull asked the attendees how many people with significant disabilities they know live enviable lives, a life of real belonging? Only a few attendees raised their hands. She asked the audience why this gap exists. Every citizen should have the opportunity to experience this life. If people realize they are traveling down the wrong around, they can still turn around. Jay's road did not lead to belonging, but to segregated marginalized living. When they took him out of the program to build their own supports for him, the director of the program said it was impossible for Jay to belong in the community. But his parents were determined to succeed. After high school there were no services or supports available for Jay. He had one activity a week as his parents hired Pat, a male personal support worker, to take Jay to the gym for an hour and a half. As it turned out this young man would take Jay to his fraternity house. He was welcomed by the other men at the fraternity house who thought Jay's presence was interesting. Also, a little hitting and choking was not out of place here. Jay belonged for the first time in his life. Pat started a program to include people with disabilities in campus organizations. This program still exists to this day. Jay became included in the university community. His job was to deliver mail. This environment was very different from the sheltered workshop and provided him with dignity. His weekly schedule started to fill up, but many barriers still existed. His parents wondered how he could belong to the general community and how community could be built around Jay and them. What would it take for people to open their doors? A focus on partnerships was needed. Group action planning in the form of person centered planning was implemented with Jay based on the principles of communication, trust,

advocacy, respect, competence, equality and commitment. There were yearly meetings, but a lot of talk did not turn to action. Belonging does not just happen, there needs to be a facilitation process. We need action to bring people together. People need to feel connected to each other in order to create a bond. For Jay's parents it was important to envision great expectations. They built a team and each monthly meeting of that team focused on a new challenge. Progress depended on team member's hard work. One or two tasks were doable for the team members. The team stayed together for four years to put all Jay's supports in place. A video of one of the meetings showed the atmosphere of energy and joy and the shared connection between the team members.

Jay worked with music therapy students each semester. Pat said it was time for Jay to move out and that the men at the fraternity house wanted to be his roommates. Dr. Turnbull noticed that once you belong, doors start to open. Doors are closed because people's networks are too small. Medicaid helped pay for Jay's housing and supports by his housemates. Jay now had a home of his own. He always went places with friends, never in groups of people with disabilities. All his goals and activities needed support but everyone in the group helped. He received control over his funds. It is important for money to follow the person to facilitate community participation. The next picture Dr. Turnbull shared was a picture of a full week schedule of Jay. Those things he valued the most were in Jay's life. All this was possible by facilitating natural resources in the community.

At Jay's memorial service, friend and colleague Mike Wehmeyer said "We are in the dignity business, not in the education or rehab business." According to Dr. Turnbull, Jay taught us that how well a sense of belonging can be created is what is truly meaningful. This sense of belonging was the essence and meaning that withstood the test of time. A question is whose responsibility it is to create that sense of belonging. Jay took the road less traveled and that made all the difference.

After Dr. Turnbull's keynote Jenny Goldschmidt commented that she made all the difference to all the attendees. Dr. Turnbull combined personal experiences with academic insights in her presentation.

Friday morning: keynote presentation by Dr. Beatriz Miranda Galarza

The first full conference day started with a keynote presentation by Beatriz Miranda Galarza. Even though she also shared personal experiences, Dr. Galarza's keynote focused more on academic theory than Ann Turnbull's keynote presentation. Dr. Galarza grew up in Ecuador and is the fourth of six children. She identified herself as a sister of disabled siblings. Her four siblings have severe disabilities. During her presentation she shared reflections on her experiences as a sister to disabled siblings. She always felt 'in between', in between her siblings, professionals and her parents. It was not easy for her to be the 'able one'. She played different roles. Sometimes she was the caregiver or the 'mother' who took care of the boys. She washed them or fed them. Sometimes she was the friend who took them out on a trip. And sometimes she could be the sister, who had fun with her brothers.

Dr. Galarza also reflected on her own belonging. She wondered whether she belongs to the community of people with disabled siblings and whether she still belongs to the country she did not live in for 3 years. Dr. Galarza's research experience revolves around narratives of siblings. She stated that community is only possible when listeners are encountered and that being a member of a community is

relational. Furthermore, she wondered what the role is of siblings in the field of disability. In the second part of her presentation she focused on the topic of performance. She stated that after the release of the movie 'What's eating Gilbert Grape', there was a lot of recognition for Leonardo DiCaprio who played a person with an intellectual disability. However, there was no recognition for Johnny Depp who played the nondisabled brother. Dr. Galarza demonstrated that being a sibling requires performance, so does belonging. Citing Judith Butler, she explained how belonging is an achievement, a dynamic process, always in transition and transformative. We play roles, and decide whether to accept them or not. The third part of the presentation focused on consciousness. Dr. Galarza stated that having her siblings opened up a way of particular connectedness for her.

Friday afternoon: Art Loca film, video presentation by Dr. Hans Reinders

During the break between the two sessions Friday afternoon, two video presentations were shown. The first video was made by Art Loca, a Dutch performing arts initiative for people with and without intellectual disabilities. This video showed Alex Naber, a young man with Down syndrome dancing with social work student Chandenie Tedjai Bollywood style. In the discussion after the video, Art Loca director Mieke van Dijk explained that Alex got interested in this particular dance style watching YouTube videos. He prepared the dance together with Chandenie and shared that he is working towards his goal of performing on live television.

During the second video presentation Professor Hans Reinders discussed what makes belonging an art. He stated that belonging means that one's presence is not only accepted, but also that one's contribution is valued. Dr. Reinders also drew attention to the binary use of the term exclusion, conceptualizing persons to be either included or excluded. Most people with and without disabilities are included in some societal arenas and not in others. Focusing on the many different social roles people can adopt throughout their lives, inclusion can be understood as a set of roles that differs between people. According to Dr. Reinders it is important to the art of belonging that people with disabilities are the agents of their own inclusion by the roles they adopt.

Friday afternoon: keynote presentation by Simi Linton

Dr. Simi Linton spoke about 'creative art of belonging' and about art as a vehicle to make disability public. She shared a series of photographs representing disability arts and culture and discussed some of the important moments in the history of the disability rights movement using these photographs. Dr. Linton mentioned the challenge of finding imagery representing non-physical impairments. It is a struggle to represent non-apparent disabilities. She stated the importance of producing art that explores what disability provides, rather than producing art based on performance despite a disability. Simi Linton furthermore explored the issue of invisibility of disability in cultural work despite the prevalence of disability. She herself can rarely relate to disability representations in the dominant cultural landscape. Disability as currently represented in character, theme and metaphor indeed seems, to those who live it, absurdly out of date and narrowly conceived. To conclude, Simi Linton shared information about her upcoming documentary 'Invitation to dance', based on her autobiographical 'coming out story'.

Saturday morning: keynote presentation by Robert Maier

Saturday morning started with a reflection by Ruth Faragher. She stressed the importance of belonging to persons with disabilities. A moment was also taken to acknowledge the buddies who have supported persons with disabilities during the conference.

Professor emeritus Robert Maier provided the last keynote of the conference during which he presented a critical reflection on the concept of belonging. After becoming familiar with the literature, reading the abstracts and attending various sessions during the conference he provided insights on the conditions of belonging, the complexities of belonging and the relationship between individual and collective dimensions of belonging. Belonging is firstly a psychological concept and refers to a bigger entity as persons belong to something. Furthermore, belonging can be discouraged or stimulated. Disability studies and the disability community have made significant strides in the development of belonging, but work remains to be done. Robert Maier indicated that belonging depends on contextual factors and has many forms. He did not recognize attention for the complexities and internal tensions of the concept of belonging in the various abstracts. As part of his final remarks Robert Maier indicated that belonging in his vision refers to wrestling with life, as provocative perspectives on reality. It is about shaking the hell out of the world. Ingrid Baart was a person who did this. Her passing is a great loss to disability studies.

Saturday afternoon: closing of the conference

During the closing of the conference, Professor Geert van Hove was presented as the new chair of Disability Studies at the VU University Amsterdam. The title of his keynote was called 'It's all about belonging: trying to find a useful balance between 'activism' and 'science'.'

Alex Naber starred again also, this time with a live dance performance. Jetta Klijnsma, the Dutch State Secretary for Social Affairs and Employment closed the conference with a short speech recognizing the efforts of all involved in making the conference a success.

Friday and Saturday: Research presentations

During the day Friday and Saturday a large group of presenters from across the world shared their work with the conference attendees. The various presentations were divided across ten streams. Below you can find impressions of several presentations in these streams.

Stream Social Inclusion and Representation

Symposium: Representation

Moderator: J.Kool

1. Mitzi Waltz When "awareness" becomes stigma: Representation of autism in charity campaigns and the media, and their impact on people with autism (O-07)

Mitzi Waltz explained that disability charities are for profit organizations that reinforce stereotypes of people with autism. The first autism charity campaign in the USA was in 1956. It had the slogan 'Children in Chains'. The international symbol for autism is a piece of a puzzle. The message of this symbol is that

we can together solve the puzzle of autism. This reference to a puzzle piece removes agency from people with autism. It iterates that autism is a problem that needs to be solved. An article about electroshocks from 1980 had the headline 'Screams, Slaps and Love'. In a lot of advertisements autism is portrayed as dangerous. Sometimes the autistic child is even framed as future terrorist if not cured.

A positive aspect of awareness campaigns is the funding it makes available for research and medications. The charities and medical industry have some of the same executives. For these executives the medicalization of autism is important to make a profit. Consequently, there is medication available that is not fully tested. An increasing number of companies aim to change this state of affairs but are also worried to lose business.

2. Katrien de Munck, Geert van Hove Who makes the Portrait? Whose Portrait is it? Portraiture as Interplay between Participant, Portraitist and Audience (O-08)

The Support Centre for Higher Education (SIHO) supports Flemish higher education in order to become more inclusive. SIHO applies the UN Convention on the Rights of Persons with Disabilities as well as a disability studies perspective. SIHO discovered that the perspective of students with disabilities was missing completely from the available research material in Flanders. After a first qualitative research project, SIHO felt the need for a method that did justice to the complexity of disability in higher education. SIHO decided to use the arts-based research method of portraiture. Portraiture gives voice to a person with a disability. A dialogue drives the portraying between art and science, by mixing research and activism and combining rigor and creativity. During the creation of a portrait the portraitist needs to have a close horizontal relationship with the participant. The one (portraitist) cannot be without the other (participant) but the participant has the leading voice. All portraits get co-constructed in an intense intra-action between the 'so-called participant' and the 'so called researcher'. This intimacy flows over to the audience, who gets connected and engaged in a new embodied understanding of the portrait. Portraiture can provide new meaning to being disabled in higher education. During the discussion one of the attendees, who is visually impaired, shared her experience with the method of portraiture.

3. Sandrine Banens "Does my daughter really belong in our society?"(O-09)

Sandrine Banens wrote a non- academic abstract about her disabled daughter Quirinne. There is no question of Quirinne belonging to the family Banens. But when Quirine wants to participate in activities every child her age participates in, making Quirine belong to society is not straightforward. Her mother shared several examples of this situation. Quirine needs specialized transportation in order to attend school. The family is confronted with bureaucracy as the city council has to decide every year whether Quirinne is allowed to use this service. It is impossible for Quirine to play outside without constant guidance. Every two weeks she visits an adapted playground where she can play safely with other children. For this service a special authorization is needed every two years as well. The Banens family needs to tackle the various obstacles bureaucracy creates before Quirine is able to belong to society. The underlying message to this family seems to be that their daughter does not belong to society, that she is a problem that costs money.

Sandrine Banens feels that belonging is not a natural thing for persons with disabilities. People stare at her daughter. They ask painful questions like whether she has ever considered ending her daughter's life after she was born. Politicians make decisions that no longer enable people with intellectual disabilities to participate in swimming at school and in school camps or to have a specialized physical education instructor available. She feels a change of direction in the Netherlands that makes it more difficult to advocate for the needs of individuals with disabilities.

Symposium: Making Inclusion Work

Moderator: M. Cardol

1. C. Platenkamp The art of belonging: about initiatives, limits and possibilities of belonging of disabled people: two messages (0-13)

The presenter shared a message that is twofold. Firstly, that there is not one way of showing the art of belonging. There exists diversity in expressing belong that depends on the context and type of disability. Secondly, each form of belonging asks different competences. The presenter used YouTube videos, online resources and other materials in her presentation on different ways of belonging. She runs a website with 2700 biographical stories of people with disabilities. Other useful resources shared were the following:

- Video Crohnuwelen <http://www.crohnuwelen.nl/>
- Magazine Unlimited <http://www.unlimitedonline.nl/>
- Freud Restaurant <http://www.restaurantfreud.nl/>
- Karin Spaink <http://www.spaink.net/>
- Jaqueline Kool <http://disabilitystudies.nl/artikelen-en-blogs-van-dsin-medewerker-jacqueline-kool> en <http://zorgethiek.nu/author/jacqueline-kool/>
- Vincent Bijlo <http://www.vincentbijlo.com/intro-keuze>
- Mathew Johnstone <http://matthewjohnstone.com.au/courses/i-had-a-black-dog/>
- Boys on Wheels <http://www.youtube.com/watch?v=AUrZi2XQKyU>
- Punk on Wheels <http://www.youtube.com/watch?v=1ivTKRSURsQ>

2. Femke Bannink, Geert van Hove Mobility, incontinence and social functioning of children with Spina Bifida in Uganda (0-14)

This research project focused on children with spina bifida between the ages of 4 and 14 at five different locations in Uganda. These children are mostly taken care of by their mothers, as fathers often leave as a result of disability of the child. Almost half of these children in need of assistive devices do not have access to them. As a consequence these children are often unable to attend school. In order to improve

the participation of children with spina bifida in Uganda interventions are needed that provide assistive devices, enable the improvement of activities of daily living, and promote the establishment of parent support groups.

3. Anouk Bolsenbroek, Willy Calis Inclusion and self-determination (O-15)

The aim of this project was to provide residents of nursing homes with pathways to increase their self-determination and to give them an equal place in society. People with multiple physical and intellectual disabilities who live in nursing homes often lack social relations outside their home or family. The presentation focused on the story of Freek. Freek is unable to share how he would like to spend his day. As a consequence he sleeps most of the time. It is clear he is not feeling well doing so. To change Freek's life a team was brought together of people who could support him. Team members were friends, family and professional support staff. The first step of the planning process involved the creation of a vision. The second step of the process consisted of listening and prioritizing, the third step of making a plan and the fourth step of celebration and monitoring the progress in the achievements of different goals. Freek's biographic story was mapped and his likes and dislikes and preferences were explored. During the planning process it became clear he wanted like to be a gardener. As a result of this process Freek got a subscription to a gardening magazine. He went into a garden to put his hands into the earth and he liked it. Freek currently is a member of a regular gardening group in his community. A volunteer takes him to this group on a regular basis. Furthermore, he became a supporter of a local volleyball team as his niece is a member of this volleyball club. He also has started making contacts with the neighbours of the nursing home.

Stream (Family) Quality of Life

Symposium: Family Quality of Life

Moderator: A. Schippers

1. I. Brown (D. Roth) Family Quality of Life: International Comparisons of 18 Studies in 14 Countries (O-16)

The first session in the (Family) Quality of Life Stream included a presentation by Dana Roth stepping in for Ivan Brown who was unable to attend the conference. This presentation demonstrated similarities in the appreciation of family quality of life of families with a member with an intellectual disability across different countries. This internationally focused presentation provided a bird-eye view on a topic to be explored during this stream of the conference.

2. L. van Heumen Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families (O-17)

The second presentation during this session featured Lieke van Heumen and four young men with Down syndrome presenting an evaluation of a family quality of life study in the city of Almere, the Netherlands

using photo voice. This presentation allowed for the self-representation and active participation of the young persons with intellectual disabilities.

Symposium: Belonging and Quality of Life

Moderator: N. Zuna

1. R. Turnbull Family support and public policy (O-21)

Rud Turnbull shared responses to conversations during the course of the conference on the theme of belonging. Firstly, he referred to Jenny Goldschmidt's presentation in which she stated that defining belonging as a right is problematic. He consequently explored the role of law in belonging. He described law as a form of behavior modification, a way to socially engineer relationships. Law and policy create a structure of human interaction and hence affect our quality of life. The law can help us belong together so we can come together. In the case of deinstitutionalization, policies can require people to confront each other. However, these policies cannot make people like each other. Rud Turnbull furthermore stated that the family is the core unit of society and deserves to be supported. This is of particular importance as the family is often the vehicle for the development of the person with a disability. He described the need for support for families with a member with an intellectual disability. What different families might need cannot be standardized. Family supports need to respond to the family's cultural values and to be determined in partnership with the family. A challenge worldwide to family support is the growing sense of individualism that tends to overtake collective needs. Relatedly, the question needs to be asked how much support the public is obliged to provide the family.

2. A. Žic Ralić The application of the oriental dance to persons with intellectual disabilities (O-22)

Anamarija Žic Ralić delivered a presentation on a study with adults with intellectual disabilities improving their well-being participating in oriental dance workshops. The study demonstrated how active engagement in meaningful activity adds to a sense of belonging of these persons with disabilities.

3. W. Buntinx What can positive psychology contribute to enhancing the quality of life of persons with (intellectual) disabilities? (O-23)

Wil Buntinx reviewed recent developments in the fields of psychology and disability to more positive interpretations of pathology and disability. As similar developments can be found in both fields, an interdisciplinary approach to positive psychology and the field of disability started to be explored in the Oxford Handbook of Positive Psychology and Disability (Wehmeyer, 2013). Buntinx explored how positive psychology can improve the quality of life of persons with intellectual disabilities. Firstly he stated the importance of professional support addressing activities that are relevant to quality of life domains. Secondly, he proposed applying Seligman's principles of positive emotions, engagement, relationships, meaning and achievement to individual support plans. Thirdly, he suggested using positive psychology principles in coaching of teams of direct support professionals.

The discussion at the end of the session combined some of the ideas brought forth by the different presenters. Rud Turnbull stated that control by families on how to spend funding for supports and services is important as they can decide to spend it on the activities that are important to them. Oriental dancing might improve their quality of life, but spending funding on this type of activity might be perceived as problematic by government agencies. The idea to have agencies apply positive psychology principles to support families to navigate services and supports was offered by one of the attendees. One of the attendees explained that all supports to persons with intellectual disabilities are provided by one service provider. A system in which this is broken down would allow for more person centered approaches that focus on outcomes that improve quality of life.

Stream Empowerment and Environment

Symposium: Belonging through Performance

Moderator: M. Bakker

1. Y. Kelders Vulnerability and the disabled body. Getting a sense of belonging through the other (0-24)

Ymke Kelders referred to the poem 'The dance of the Day' to make clear that a physical impairment is linked to dependency of the other. Vulnerability can be seen as the property of the other and as the paradox of neo-liberal politics in relation to disability. Through an analysis of this poem and the PGB (a personal budget from the Dutch government for persons in need of support) Kelders tries to reconceptualise the notion of the disabled body in relation to the health care system of the Netherlands and the influence of neo-liberal standpoints.

The Netherlands shifted from a welfare state to a 'participatory society.' As there is less funding available people are held responsible for their own care and are required to be more self-sufficient. However, the level of support needed by individuals is similar. Kelders claimed that the governmental demands are based on a non-existent society. In a participatory society there are still bodies in need of care. These bodies depend on others. Disabled people belong through the other and are in a way 'owned by the government.' The changing rules require a critical gaze that goes beyond neo-liberal fixation with being independent.

2. Hilje van der Horst, Maartje Hoogsteyns Technical aids, aesthetics and the mediation of belonging (0-25)

The general assumption underlying this presentation was that people who use technical aids passively endure a stigma effect of their aid. The presenter posed the questions how people deal with this stigma, whether people tinker with a technical aid and how this impacts their experience of disability. To inform their project the researchers studied 'Art and Agency: An Anthropological Theory' by Alfred Gell (1998). Gell examined the power of (art) objects and their distributed agency and personhood. Van der Horst and Hoogsteyns also conducted interviews using the biographic narrative interpretation method. Aesthetics of technical aids were found to intervene in the way in which people could relate to others and to their impairment.

A case study of a man called 'Wim' was presented. Wim, a former mechanic, lost his arm because of an accident and is no longer able to occupy his profession. On a trial basis Wim got the opportunity to help develop his own prosthetic arm. He chose for a design in which the technique used is visible. In other words, the prosthesis looks like a robot arm. The artificial arm is specially designed for Wim. He tinkers with his prosthesis. His aid gives him the opportunity to showcase his knowledge about engineering, to share how he developed his arm and to talk about his impairment. Tinkering depends on context. Wim's family at home is not interested in the technical workings of the prosthetic arm. They know Wim and his story already and also witness his frustration about losing his work. There are also aids people prefer to be invisible such as incontinence materials. People also tinker with these hidden aids. Hoogteyens en Van der Horst were told by a young woman that she cuts her incontinence material to a more suitable size so she is able to wear her own clothes. Another example comes from a man who needs to use incontinence pants. This man needs to carry a bag with his incontinence materials. It is unusual for men to have a bag with them all day (in contrary to women), so he bought a really expensive suitcase as a nice way to carry his materials with him.

3. Sander R. Hilberink, Mieke Cardol Agency in the 21st century: the emperor's new clothes (0-26)

At the present time, agency often suffers from a 'more is better' paradigm. Agency usually refers to a type of citizenship that fits general expectations, lacking concepts as diversity and variety. In policies agency is considered as an outcome, which unilaterally places greater emphasis on one's own responsibility, while limiting the needed support systems to enable that very responsibility. This makes citizens vulnerable to the loss of agency over their lives.

Agency seems to be annexed by policymakers, being stripped from actual lived experiences and the right for self-determination; agency has been transformed from the endeavour for ownership of one's life into a verdict to enforce active citizenship without offering the required support. It appears that agency is now reintroduced as the 'emperor's new clothes.'

Symposium: Adapting the Environment I

Moderator: J.Kool

1. Susan Flynn Avatar: Ableism and Normalization (0-27)

The presenter stated that the popular Hollywood movie Avatar legitimizes the stereotyping of disability and showed examples of how the movie is glorifying the healthy body. In the movie the protagonist with a disability is dreaming of a healthy body. He is frustrated that he is still paralyzed when he wakes up. In reality he is paralyzed, but as the Avatar he is not. In the Avatar world movement of the body is exhilarated. In the real world the disabled protagonist never stands eye to eye with other persons and has no real contact with others. In contrast, as the able bodied Avatar he has intimate relationships. The presenter argued that this movie presents disability as a totalizing identity and that the main agenda of the film is normalcy. The main goal of the protagonist is to be cured and a 'normal' body is assumed to be important for everyone.

2. Maartje Hoogsteyns How to turn technical aids into social mediators (O-28)

The presenter explained how the definition of what entails good care has been changing. There has been a shift from cure to care from a focus on curing the individual body toward a more contextual and socially embedded notion of how to live a good life with impairment. She posed the question how to turn technical aids into social mediators. Aids can be functional, repairing or increasing and have social consequences. A growing group of people needs an aid. Based on 27 interviews the researchers concluded that the arrival of a technical aid in a home setting can change relations between family members as well as the experience of being impaired. This underlines why it is important to reevaluate technical aids from an ethics-of-care perspective.

3. Petra C. van der Kaa Creating a positive view (O-29)

Hearing problems are mostly seen as an impairment of older people. Most advertisements for hearing aids are focused on older people. The needs of young people with hearing problems are not considered in the same way. Younger persons with hearing impairments distance themselves from older people and feel ashamed about their aid. They desire their aid to be invisible. Petra van der Kaa wanted to improve the imaging of hearing aids and photographed young people with their aid in an aesthetically attractive, non-medical, way. The aim of the project was to show that young persons with a hearing impairment exist and that they are proud of themselves.

Stream Inclusive Employment

Symposium: Participation through Paid Work

Chair: W. van Brakel

1. K. van Brakel Can't do it on their own; The work participation of young disabled persons in the Netherlands (O-33)

The Dutch government recently changed the law on employment of young persons with disabilities in order to focus more on ability rather than disability. The influx of young persons with disabilities into the Insurance Act ('Wajong') is about 16.000 persons per year. Two thirds of this group is made up by persons with intellectual disabilities. A quarter of this group has either regular or sheltered employment. Sixty percent of the young persons with disabilities in regular employment need some form of support. Thirty five percent of them have a job coach.

For most young people with a disability participation in paid work is only possible if they receive enough support. The UWV (Dutch Employee Insurance Agency) provides this support. However, employers themselves often arrange support as well. Many times they do so with the assumption that support is only needed in the beginning of employment and that the employee will be able to work independently after several months. For many persons with disabilities, especially for those with intellectual disabilities, this situation is not feasible. As a consequence employers can become disappointed.

One of the attendees remarked that there are also people with disabilities who work and do not receive any benefits or supports. This group is out of sight of the UWV. Furthermore, even though the term 'young person with a disability' ('Wajonger') is used, not all persons receiving these benefits are actually of a young age. The term only refers to the age of onset of the illness or impairment.

One person asked what actions the UWV takes to meet the wishes of the employers. Employers need financial compensation. A job coach is needed for sustainable employment. Employers can be open to hire someone with a disability, but they are not going to actively look to hire a person with a disability. They want candidates to be presented to them. Furthermore, they state that it is easiest to make adaptations for persons with physical disabilities versus for persons with other types of disabilities.

2. B. Cornelius High prevalence of early onset mental disorders among long-term disability claimants (O-34)

Due to illness Mr. Cornelius was unable to present.

3. T. Araten-Bergman Employment, Social Capital and Community Participation among Israelis with Disabilities (O-35)

The presenter stated that persons with disabilities have limited opportunities to gainful employment. The assumption is often that employment automatically leads to social integration. However, employment does not necessarily mean persons experience integration in community life.

Employment is most often found by individuals through connections in social networks. People who are less integrated in social networks and community life are less likely to find a job. A lot of people with disabilities are not integrated in social groups. They are not connected with the right networks, even if they have the education and skills needed to be employed. Furthermore, without adequate information they miss opportunities to find paid work.

The concept of social capital investigates not only employment issues, but also addresses institutional ties and civic attachments. The presenter explained that there are several types of social capital. A distinction can be made between bonding social capital and bridging social capital. Bonding social capital revolves around social networks. People that are excluded of social networks are not in the loop. Bridging social capital is about links across heterogeneous societal networks. Social capital experienced by persons with disabilities has not been researched sufficiently, especially on the individual level. Hence, this is the theme of Araten-Bergman's research.

The presenter concludes that exclusion from one sphere of life is associated with a higher risk for exclusion in other life spheres. To the researcher's surprise, people with more severe disabilities are most likely to be employed.

During the time allotted for questions and discussion several attendees remarked that it is often easier for people with visible and more severe disabilities to find employment. Several reasons were suggested for this observation. One could be that employers can use them for the purpose of window dressing.

Another reason could be that the person experiences the disability as more severe as they might be more confronted with their disability because they are employed.

Pancocha (who held a poster presentation at this conference) stated that his research results on employment for the group of people with physical disabilities were similar. People with more severe impairments were the ones who held the most jobs.

The research of Araten compared people with disabilities in employment with people with disabilities who were not employed. A suggestion to the researcher was to make a comparison between persons with disabilities who are employed and employees without disabilities. Aratan stated this would be interesting for a next project.

During the continuation of the discussion several international attendees shared the situation regarding employment of persons with disabilities in their respective countries. In Indonesia, employers are mandated to employ persons with disabilities so they represent 1% of their workforce. The problem in this country is that persons with disabilities often do not have enough qualifications to be employed. In Georgia the government has recently started to consider the subject. In the Czech Republic support to employers is provided by NGO's, not by the government. In the Netherlands, the UWV has found that finding employment is easier than maintaining employment for persons with disabilities. Employers want to hire someone with a disability, but they do not realize that the employee needs ongoing support.

The question was posed whether it is fruitful to engage volunteers in promoting employment. The response by several attendees was that this is not effective as to maintain continuity it is important persons are paid.

Symposium: The Essentials of Belonging: Inclusive Employment

Moderator: K. Vornholt

1. G. van Ruitenbeek Experiences with the Method 'Inclusive Redesign of Work Processes' (O-36)

As Dutch law will change from establishing a right to work to an obligation to work for people with disabilities the creation of employment opportunities is necessary. There is a gap in the current labor market. Vacancies cannot be filled at the same time that there are many unemployed people. Job carving is a task-oriented approach often used to create non-complex work for people with disabilities. Researchers at Maastricht University in the Netherlands have developed a new approach to the design of employment for persons with disabilities, called 'Inclusive Redesign'. Inclusive redesign uses a process oriented approach. It aims to create non-complex work in regular workplaces by redesigning the work processes of the organization as a whole. This approach was for example used in a healthcare setting. Nurses do a lot of administrative work as well as cleaning. These tasks can also be done by persons with disabilities. Using this approach the nurses had more time for more complex tasks.

One attendee asked whether this approach to employment will replace sheltered employment. The presenter stated that inclusive redesign aims to create jobs with regular employers and that for some people with disabilities a sheltered workplace will always stay necessary.

It was also commented that not all persons with disabilities want to do non-complex work. The presenter stated that this is true, but that the aim of this approach was to create non-complex tasks. The majority of the group has an intellectual or developmental disability. Most of them are not able to do more complex work. If they are, they can use the jobs as created through this project as a stepping stone to alternative future employment as it is often problematic for them to enter the labor market.

Another comment was that the higher educated workers (e.g. the nurses) find it meaningful to spend some of their work time doing non-complex work themselves. In the opinion of the presenter, higher educated personnel gets paid to do the more complex work.

One attendee asked whether the research team at Maastricht University is also helping organizations to create work or whether it only does research. The presenter stated that it is important for the university to collaborate with employers and management of large organizations. The assignment to use inclusive redesign needs to come from an organization in order for them to support implementing it. The researchers only collaborate with employers and organizations willing to redesign their work processes in order to hire people with disabilities.

2. K. Vornholt Acceptance of People with Disabilities at Work. A literature review and validation of a newly developed questionnaire (O-37)

Vornholt's research concerns the acceptance of people with disabilities at work. The presenter focused on the importance to have more knowledge about this acceptance and how it can be measured. Being employed is essential to individuals' mental health and well-being. However, only being employed is not sufficient. Many people with disabilities indicate that they feel stigmatized and excluded at work. Vornholt and colleagues therefore pose that being accepted in a group of colleagues is a pre-condition for the experience of beneficial effects of work. Acceptance is needed to create sustainable employment for people with disabilities.

The research question was which factors influence the acceptance of people with disabilities in regular employment settings. Social acceptance occurs on a continuum that ranges from merely tolerating another person's presence to actively pursuing someone as a relationship partner. Acceptance has three dimensions. It includes cognition, affect, and behavior. The cognitive dimension refers to the thoughts, ideas and beliefs that people have about a person; the affective dimension is referred to as the emotions that people have towards another person and the behavioral dimension consists of people's actions in relation to a co-worker for instance. An employee with a disability is accepted when he or she is treated as a full member of the working community and when colleagues accept the disability as a natural attribute of their co-worker and reward the performance of their disabled colleague.

The results of the study indicated that the acceptance of employees with disabilities is influenced by the characteristics of co-workers, the characteristics of the person with a disability himself, and the employer and organization. Job performance is one of the most important factors in the acceptance of

the person with a disability. Work tasks are often interdependent. A lower performance is perceived by coworkers as needing to work harder. It is therefore important to create tasks that people with a disability can actually fulfill, so they will be able to have a good job performance. More collaboration between employees will lead to more acceptance of the person with a disability. Many gaps remain in the understanding of the concept of acceptance. Vornholt will therefore continue research in this area.

3. P. Nelissen The Building Blocks of an Inclusive Climate (O-38)

During this presentation Nelissen presented his research on creating inclusive organizations. An inclusive organization is an organization that optimally uses the diversity of talents and capabilities available in the labor market. This type of organization is capable to attract and sustain people with disabilities and to prevent employees with disabilities from prematurely dropping out.

The work participation of people with disabilities at regular organizations fluctuates strongly. There is a high turnover rate. Nelissen found in his research that only 50% of people with disabilities were able to retain their job for a period of one year. So the question rises which conditions are necessary to achieve a higher degree of participation, inclusion and sustainability of employment. In other words: what are the building blocks of an inclusive climate?

In his research Nelissen looked at this theme by addressing the perceptions of the employees and their opinions on the way people with disabilities are accepted, helped and treated by others in the work environment. He did not look at the level of acceptance of the supervisor or management. The conclusion of his research was that there are factors at the team level that lead team members to display more inclusive behavior, regardless of the individual features.

During the discussion it was stated that the role of the supervisor is also important in creating an inclusive work climate for persons with disabilities as he or she sets the tone in the development of the team. The perceptions of the employees and how willing they are to help their disabled colleague is influenced by the perceptions, level of acceptance of the supervisor. An attendee asked why Nelissen did not address this topic in his research. Nelissen answered that it could indeed be interesting to investigate the level of acceptance of the person with a disability by the supervisor. Supervisors can encourage inclusive behavior of their teams. They can create an inclusive and safe work climate.

Stream Inclusive Employment

Symposium: Work as Catalyst for Belonging

Moderator: W. van Brakel

1. T. van Wieren Autism Spectrum Disorders and Intellectual Disabilities: Private- Sector Workplace Discrimination in the U.S.A. (O-39)

Persons with autism spectrum disorders (ASD) form the fastest growing disability group in the USA. In this country the incidence of ASD diagnoses grows with 10-17% each year. Many people with ASD can be successfully employed given they experience a good fit with the specific workplace and receive

adequate supports. In reality 50-75% of the adults with ASD are unemployed. Most of the current ASD research focuses on either childhood issues or medical and psychological treatment of ASDs. There is not much research available on the experiences of adults living with ASDs. Many persons with ASD are placed in the retail industry, as this industry offers low-level entry jobs. But this industry does not necessarily provide the best fit. Furthermore, most discrimination claims are concerned with maintaining a job, not with getting a job.

3. C. Aarnoutse Key elements in transition from school (VSO) to employment: a survey and a new approach (O-41)

Mario Nossin stepped in for author Corry Aarnoutse to give the presentation. He mainly used his presentation to share the vision and way of working of the Dutch organization 'Perspectief' as he is the director of this organization. Perspectief is a resource center for inclusion and self-determination. It is part of the larger Dutch network "Coalition for Inclusion". Perspectief is always working *with* people with disabilities. One of the projects of Perspectief is called "Perspectief werk(t)" (Perspective Employ(ed)). Another project is the SEARCH project. Because Nossin was not familiar with the project details, this part of the presentation was brief. Instead Nossin focused on presenting a vision about inclusion. In his view (and the mission of Perspectief), it is important to move from building structures to building communities.

The project "Perspectief Werk(t)" focuses on transition from special education to work for people with disabilities. A survey was conducted. One of the outcomes was that the main orientation is towards care provision and not towards finding a job. Young people with a disability are led to the "Wajong" (Dutch benefits for young disabled people) and not towards finding a job. The school, together with the allowance funder decides who gets a benefit and who does not. If people with disabilities are supported towards work, this is oriented towards lower-paid job. The expectations of the schools for these young disabled people are low. There is no focus on continuous (life-long) learning. Low societal expectations were found to be the single most critical constraint to programs for persons with severe disability.

During the general discussion following the presentations Mr. Nossin pleaded for a 'participation budget', a financial means to be used by persons with disabilities to purchase their own support in the broader area of participation. This would allow support of personal development and participation goals which is not allowed for personal budget ('PGB') users in current Dutch policy.

Stream Friendship

Symposium: Hybrid Spaces of Belonging

Moderator: G. van Hove

1. C. Shpigelman Social media and people with intellectual disabilities (O-45)

Carmit-Noa Shpigelman spoke about a research project exploring the use of Facebook by persons with intellectual disabilities and the value of this social media platform for the development of relationships of this group. However, this platform also has barriers for use by persons with intellectual disabilities.

She referred to the importance of using simple language to improve accessibility. One attendee mentioned he prefers the word 'clear' language over 'simple' language to be more respectful to this group. However, it could be argued whether both words are truly synonymous. The point is well taken though that sensitivity and careful deliberation is needed in order to respectfully represent persons with intellectual disabilities and their needs.

2. H. Meininger Inclusion as Heterotopia: Spaces of Encounter Between People With and Without Intellectual Disability (O-46)

Herman Meininger provided the attendees with a reflective philosophical exploration of the meaning of the concept of deinstitutionalization. Herman Meininger stated how policies of deinstitutionalization have resulted in a continuation of institutionalized regimes. Persons with intellectual disabilities still find themselves on the margin of society in segregated settings. Social inclusion needs more than physical integration to come to fruition. By focusing on social aspects of Foucault's heterotopia (other spaces) Meininger sketched a 'new heterotopia' and invited for dialogue between normal and abnormal, familiar and strange. A new heterotopia without walls de-territorializes 'other places' and can become an environment of acceptance, hospitality, dialogue and of suspension of instrumental rationality and the ideology of normality.

3. G. Dingle Focus on Friendship; (dialogue) conversations about social relations with secondary schools and their students with autism (O-47)

Gigi Dingle closed the session with a practice oriented presentation focusing on friendship projects in secondary education classrooms of students with autism using the dialogue method. This method will be applied at a second school this coming winter and an evaluation is to follow in 2014. A disability studies perspective was not at the foreground during this presentation.

Symposium: Reciprocity and Friendship I

Moderator: G. van Hove: "Does everyone have the support they need?" Answer: "Yes, we have coffee!"

1. D. Milton "Welcome to the machines": autism and the acquisition of tacit knowledge (O-51)

The ontology of what autism is has been discussed for a long time. There seems to be a tension between belonging and autism. People with autism are said to have no empathy, no social reciprocity and no Theory of Mind. Autistic people are sometimes seen as less than human and as animalistic or machinelike. The author stated that people with autism spectrum disorders are social beings as well, just different social beings. Autistic people often have the sociality of an outsider. Reciprocity is an important concern for autistic people. The presenter used the work of Collins and Evans (2007). According to Collins and Evans, the primary source for the acquisition of knowledge and expertise is social. The presenter posed the question how this relates to the acquisition of knowledge by people with autism.

Collins and Evans (2007) make a difference between polymorphic and mimeomorphic actions. Mimeomorphic actions are performed in the same way each time and thus can be reproduced

mechanically. Polimorphic actions depend on the context for interpretation and continuation and thus are not reproducible by machines. Polimorphic actions require social understanding and flexibility to adapt actions to changing social contexts.

It could also be argued that autistic people, if one is to believe current dominant ideologies regarding what autism 'is', are machine-like, unable to appropriately replicate the behaviours and understandings of non-disordered humans. Not all autistic displays of knowledge and expertise can be explained away as highly honed mimeomorphic actions. If autistic people were primarily machine-like, then where do the idiosyncratic expressions of autistic people (Mullin, 2009) originate from?

Collins (2010) points out that domesticated animals, whilst immersed in human society are not able to be socialised, in the sense one does not encounter vegetarian, arty, or 'nerdy' dogs, they are simply just dogs. Yet one does encounter autistic people who are vegetarian, artistic, and certainly 'nerdy'. Autistic people have distinct interests and abilities that involve social practices, and this includes those who are deemed 'non-verbal' who are often musical or artistic, and whose bodily movements have been argued to be a form of language (Baggs, 2007, Milton, 2012c). Those who build a capacity for social communication are not limited to those deemed to have 'mild symptoms', but the vast majority of those on the spectrum (and to some extent all on the spectrum).

The differing sociality that is produced from autistic ways of being are often stigmatised for not abiding by so-called 'simple' ubiquitous expertise, leading to a lack of opportunities for extension into the social world, finally resulting in alienation, anomie, 'problems in living' (Milton, 2012e), and a vicious cycle of psycho-emotional disablement (Milton, 2012f). The conclusion of the presenter is that Collins and Evans are not well informed about autism.

2. F. Renders Givers and receivers: auto-ethnographic stories and self-reflections about life in a Flemish institution for people with an intellectual disability (O-52)

Frank Renders' PhD research was based on the writing of his auto-ethnographic story about his experiences as a direct support professional in an institution for persons with intellectual disabilities. He stated that the untold stories of the caregiver are interesting as they shed a light on the invisible world of the institution. He further posed the question what can be done with these stories inside the institution. A separate place is needed for these stories as a safe environment is needed to share these personal stories. Renders does not want to become an object of study for a psychologist or psychoanalyst when he shares his personal stories and experiences about working in the institution for people with intellectual disabilities. The stories should have consequences on a relational level, not on a hierarchical level such as the institution's management as that can have consequences for caregiver's jobs. Renders further stated that it was difficult for him to write auto-ethnographic stories, because they were not allowed by the institution and were considered clandestine.

3. E. Nathan Unfolding the Proposed World We Can Inhabit Together: 'Belonging' in Art and Theology (O-53)

The presenter brought forth that theology is normally not part of the conversations in Disability Studies. He stated that he hopes this situation will change as theology can be a dialogue partner in this project. Nathan showed several artworks and pictures and used a picture of the Berlin wall as a metaphor. It was a dream of the people for this wall to come down. In order for this to happen, people needed to be involved and actively participate. In the present time we have other walls, such as hate or poverty. A picture of a flight of stairs, with one person left behind demonstrated that as we move forward, we should also look back and make sure people with a disability can follow.

He further explained the Christian concept of 'agape'. Agape is about caregiving and has brought a new form of exclusion for decades, until a social model started to evolve. Another concept he discussed was 'mutual indwelling'. The strangeness of the other is what we dwell or commune into.

During the discussion it was remarked that both Frank Renders and Damian Milton talked about distance to people. Renders used this distance as a form of respect to his clients, and he needed it to be capable of reflection. Milton said autistic people feel distance to other people because of a different sociability and that non-autistic people feel distance to autistic people and/or treat them as different. Nathan instead had put the concept of 'mutual indwelling' on the foreground. This concept is not about distance, but about unity. The question was posed how the concepts of distance and mutual indwelling relate to each other. Nathan stated that in the end, unity is possible. Milton stated that the distance is partly caused by stigmatization. Distance caused by institutionalized can be a problem. Renders explained he needed the distance to be able to reflect and write his auto-ethnographic stories.

One attendee asked Renders whether his stories created a new entity or a new form of distance and whether it would not be better to create stories with the disabled people in the institution where he worked instead of writing about them. Renders said that for him the untold or invisible stories of people working in the institution were interesting.

Stream Workshops

Workshop: Belonging in Education

Moderator: J. Jansen

1. J. Jansen Universal Design for Learning: belonging to education (O-63)/ 2. K. de Munck Universal Design for Learning: How can we make it everybody's business? (O-64)

This workshop consisted of a lecture about the concept of Universal Design for Learning (UDL). The presenters represented the Dutch organization for Handicap and Study (Judith Jansen) and its Belgium counterpart, the organization for inclusive higher education SIHO (Katrien de Munck). SIHO and Handicap + Study collaborate in this project.

The presenters started by asking the audience what their favorite way of learning is. Answers included reading, listening, talking, having a discussion, using YouTube or using a mixture of styles. An attendee shared that she can only learn if she becomes inspired. The thing she needs to learn has to touch her and affect her. Learning is not only about the content of information presented but also about the way it

is presented and about how the information is taken in. UDL is based on the results of neurocognitive research. There are three major networks in our brain that play a role in learning, the recognition network, the affective network and the strategic network. In UDL these three brain networks are addressed.

UDL is about multiple means of representation, multiple means of action and expression and multiple means of engagement. Content is presented in multiple ways, students are given multiple pathways to present what they know and they are allowed to make choices in activities.

Universal Design for Learning is based on the concept of Universal Design. This concept (Universal Design) is used in architecture. When buildings are designed, they should be changeable from the start. This means they should be built in a flexible way to allow for later adaptations.

Analogous to this line of thinking, Universal Design for Learning is about designing flexible ways of learning. It should be possible to make adaptations at many points in time. Designing learning environments is a continuous process with no specified beginning or end. This is true for the built environment, but also for the learning content.

This flexibility is a challenge for universities. At least 10-12% of the students in higher education has a disability. Universities are made responsible by law to incorporate inclusive design in the built environment. With the implementation of the UN Convention on the rights of people with disabilities educational systems need to also consider implementing inclusive ways of (re)designing their teaching material.

The mission of Handicap + Study and SIHO is to spread the concept of UDL. Because UDL is a new concept and most teachers and schools and universities have never heard of it before, the first step is to raise awareness. Handicap + Study and SIHO started with a training of a small group of teachers from their own network. This group spread the word, which resulted in another group of people following the same training and so on. The ultimate goal is that schools implement UDL in a sustainable way. At the end of the workshop the presenters asked the audience to brainstorm about their own teaching and learning environments they participated in during the last five to ten years, to think about how the learning was designed and what changes they would like to see in the future. Attendees for example wanted to have control over the teaching environment and to have multiple ways of presenting information to students.

An attendee remarked that it is important to inform students about how they can best perform in a job with their possibilities and disabilities after they have finished their study. Currently a gap exists between education and employment. UDL is about keeping the expectations of the students high but offering them different ways to reach their learning goals. UDL is focused on education. The attendee stated that for people with disabilities the problem lies in finding a job, *after* finishing education.

It was noted by the audience that it is important to find a balance between flexibility and structure. Students want to know what their goal is, where they are heading towards. Too much flexibility is not

always what students want or need. The presenter stated that UDL is about how we can make learning possible. We should make learning possible for all people regardless of learning style.

Another example of an application of UDL is the designing of evaluation. Currently forms are most often used for evaluation. Students should be able to express their experience which is often limited with the use of forms.

Stream Inclusive Education

Symposium: Belonging through Education II

Moderator: W. van Brakel

1. Stephanie Claus, Elisabeth de Schauwer, Geert van Hove, Karen Leyman, Meggie Verstichele, Lies Tijtgat, Anselme Derese "I just want them to see me as Lisa, not as the one with a disability!" How students with a disability try to find their way in a Faculty of Medicine and Health Sciences (O-69)

The aim of this project was to look at strategies of students with a disability in finding a place in the dominant medical and achievement based discourses at a college of medicine and health sciences. As described below Foucault's concept of transgression was applied to describe movements students make to maintain themselves at this university:

1 concealing difference: "I'm not disabled."

2 Struggling with normality: "I'm a normal student."

3 Showing ones capabilities: "I'm not my disability."

4 Using a label as a beacon: "My label is my proof."

5 Repeating forms of exclusion: "A person with disabilities can't become a doctor."

Movements can be flexible, can consist of a transformation of passive individuals to active agents, exist between belonging and not belonging and can be a process with moments of belonging and of not belonging. Most of these movements can be seen as a way of transgressing the disabled identity in order to receive recognition as a student and as a person with capacities. These movements reject persons with a disability as passive and disability as a fixed given.

2. Inge Bramsen, Mieke Cardol Educating healthcare students to listen to the insider perspective of people with disabilities (O-70)

This presentation focused on the question why it is important that medicine students learn to listen to people with disabilities. The presenters argued it enables diverse perspectives on disability that represent insider views, transcend a dominantly medical discourse and frame disability as a social construction.

People with intellectual disabilities experience stigma influencing their sense of belonging to the community. Support professionals play an important role in the lives of people with intellectual disabilities. Students interviewed people with intellectual disabilities and each other. This revealed several themes are important for the sense of belonging of persons with intellectual disabilities and the students themselves.

3. Philomene Op 't Hoof, Ariene van Westen From text to texture. Count me in, a curriculum for educating the excluded (O-71)

The purpose of the Space Station project 'Count me In' was to develop a mainstream curriculum for people who are in need of intensive support. The Space Station crew organized over sixty drama workshops. Drama was a powerful vehicle for education and to cope with emotions. The aim of the project was to educate, to enhance and to include.

Stream Public Policy and Rights

Symposium: The Rights of Belonging

Moderator: E. Luytzen de Vos

1. Y. Cantin French Deafs during the 1900's period : a fight for equality (O-75)

Yann Cantin provided a historical perspective on the fight for equality of D/deaf persons in France between the 1880's and 1940's. The fight of Deaf people and of people who became deaf during the first World War was different. Deaf people fought for cultural equality through the use of sign language. Cantin's research focus was on how Deaf people rejected social assistance as requested by people who became deaf during the war. Deaf people also rejected inferiority by paying war tax.

2. P. Björne Self-determination and participation – implementing qualitative aspects of Swedish legislation on disability (O-76)

In new legislation for supports of person with disabilities in Sweden quality needs to be defined by users but the quality of services is often found to be poor. There is no plan in place for testing the quality of services after the legislation is enacted. As a policy maker in Sweden the presenter used narrative inquiry with support staff of service users with challenging behaviors. Staff stated that the new law required too much and that persons with disabilities are unable to live good lives. With this law persons need to prove they are not like others in order to receive services. The operational definition of good quality supports should not be for persons with disabilities to live like others, but to be like others in choosing their own life.

3. A. van Wijnen Large Scale Listening: Monitoring the implementation of the UNCRPD in the Netherlands (O-77)

The aim of the project Agnes van Wijnen presented is to continuously follow the experiences of a large number of persons with the implementation of the UNCRPD in the Netherlands. The method used for

this is based on large scale listening and uses an open internet platform that allows use of text, photos and videos. This strategy provides an example of inclusivity in research methods as persons with disabilities and other stakeholders can represent their experiences themselves. Furthermore, the project is not defined by researcher's hypotheses. A comment was made by an attendee asking for awareness of accessibility of such a platform for persons with intellectual disabilities. Videos with sign language can also be uploaded to the website.

Stream Participation

Symposium: Participation: Belonging Together

Moderator: M. Cardol

1. M. Cardol Participation in terms of belonging to this AND that (O-78)

Mieke Cardol represented the views on participation and belonging of persons with disabilities on a continuum from an individual to a social perspective. Often the focus lies on differences between people with and without disabilities when describing belonging and participation. Mieke Cardol posed the question what would happen if we would not focus on differences. Using the work of the philosopher Deleuze, she explained that identities are not fixed and that people search for the opportunities to become who they are. Striated, organized places and smooth, fluid places always occur together. Striated places can make people feel safe and smooth places allow people to become who they are. The presenter used this perspective to explore the participation of persons with intellectual disabilities who are also visually impaired. She visited these persons for several hours at a time. She found that the persons with disabilities participated in small worlds but that belonging also happened in these settings. Thinking about the differences in striated and smooth places can help facilitate participation. Deleuze's theory helps look at participation from a more dynamic standpoint.

2. L. Claes "Longing to belong." Spaces of (non-)belonging in the life trajectories of people with intellectual disabilities and additional mental health problems (O-79)

Lien Claes presented her ongoing PhD research. In the background of her presentation she discussed how society is becoming more complex which produces feelings of alienation and experiences of longing and not belonging. These risks hit vulnerable people more. Her study is situated within the interdisciplinary space between disability studies and social geography focusing on the experiences of social spaces and implications to belonging of persons with disabilities. Lien Claes defined belonging as a combination of social practices and emotions and as a concept broader than inclusion. She stated that it is important we move beyond the dichotomy of inclusion and exclusion as we are both included and excluded. The spaces of belonging of persons with disabilities are liminal spaces of being 'in between'. In the stories she explored the longing to belong was present. To conclude she put forward a relational perspective to disability to understand belonging. Relationships to people and places in the past also have an influence on current belonging.

Both Mieke Cardol and Lien Claes provided extensive theoretical backgrounds to their work.

3. R. Dalemans (S. Stans) Being there: Social Participation through the eyes of People with Aphasia (O-80)

Steffy Stans stepped in for Ruth Dalemans who was unable to be present. The current study moved beyond quantitative understandings to the experiences of persons with aphasia with participation. Thirteen people kept a diary made accessible with the use of pictograms and bold text six months after onset of the aphasia. The diaries were then used in interviews. It was found that it was important for persons with aphasia to be present in social situations. Supports are needed to make those spaces smoother.

Concluding remarks

We can look back at a successful and dynamic conference with valuable contributions of participants from a wide variety of disciplines, backgrounds, nationalities, interests and talents. In addition to reflecting on the art of belonging in the context of disability as a construct it also made many of us reflect on our own belonging and develop belonging together. Intellectual disability was strongly represented during the conference, both by the presentations from the attendees as well as by presentations from self-advocates. This reflects the growing attention for this marginalized group in development of disability studies both inside and outside of the Netherlands. We hope the conference has informed and inspired all attending in our work to improve the lives of persons with disabilities around the world.

Sponsors

ZonMw, St. Instituut Gak, Achmea, UWV, ASVZ, Stichting Beelden van Kwaliteit, EsDeGe Reigersdaal, De Raphaël Stichting, 's Heeren Loo, De Hoogstraat Orthopedietechniek, Stichting Pameijer, SizA, Arduin, Ipse de Bruggen, Bartiméus, Merem Revalidatie, VU, Sherpa, Hogeschool Rotterdam, Abrona and Leprastichting.

On the authors

Ms. Lieke van Heumen is a doctoral candidate in the Disability Studies Program at the University of Illinois at Chicago.

Ms. Karin van den Bosch is the owner of Karins Consultancy. She works as a freelancer for several Dutch organizations, including Disability Studies in the Netherlands.

Ms. Lotte Werkema currently works as project staff for Disability Studies in the Netherlands.