

DISABILITY STUDIES CONFERENCE

'Diversity in Quality of Life'



PROGRAMME

December 2 - 4, 2010

**Amsterdam, The Netherlands
VU University Amsterdam**

www.disabilitystudies.nl

Support

The Organising Committee gratefully acknowledges the following sponsors for their support in realizing this conference:

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Omdat niemand hetzelfde is ...



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Welcome

Dear colleague,

On behalf of *VU University Amsterdam* and *Disability Studies in Nederland (DSiN)* it is my pleasure to welcome you to Amsterdam for the first international disability studies conference in The Netherlands. We are especially delighted to have this conference on Friday December 3rd, which is *International World Disability Day*.

'Disabilities studies' names a relatively new approach in the academic world to disability as a social and contextual phenomenon. It starts from the conviction that disability is part of the human experience, and that it matters how this experience is constructed in society. Not only does it matter for how people with disabilities are treated, but also for how society deals with diversity and difference. With this approach disability studies supports the view that disability is an experience to be understood rather than a problem to be solved. This means that including personal experience is crucial to the production of scientific knowledge in this field.

We are very pleased that *Disability Studies in Nederland* has been enabled to lay out a trajectory for funding research, and the first round of projects has been accepted earlier this year. The long term goal of this trajectory is to integrate the disability studies approach in the relevant disciplines in higher education and academic research in The Netherlands. *DSiN* is happy to celebrate this successful start on occasion of its first anniversary.

We are equally pleased that VU University supports this event on occasion of its 130th birthday, as part of the lustrum agenda *Freedom and Responsibility*. VU University is renowned for its continuing interest in social and cultural issues on the scientific agenda, and we hope that this interest will lead to future cooperation on disability issues in the future.

To promote the disability studies approach in The Netherlands the conference will focus on a key concept in mainstream academic approaches to disability, namely 'quality of life'. It raises the question of how this concept can be used in a disability studies perspective that starts with the stories experiences/perceptions of the people who are personally involved in disability experience.

The organising committee wishes you a conference that will prove fruitful for your own work and reflection. We hope you will enjoy the Dutch capital in this time of year, when it is preparing for the Holyday season, and that you will share the city's creed: **I amsterdam**.

On behalf of the organising committee,

Ingrid Baart (VUmc), Wim van Brakel (VU), Jacqueline Kool (DSiN), Alice Schippers (DSiN),

Hans Reinders
Professor of Ethics
VU University Amsterdam

Chair

The logo for the city of Amsterdam, featuring the word "I" in red and "amsterdam" in black, with a white shadow effect behind the letters.

Organisation

Organising Committee

Ingrid Baart	VU University Medical Center
Wim van Brakel	VU University Amsterdam
Jacqueline Kool	Disability Studies in Nederland
Hans Reinders	VU University Amsterdam
Alice Schippers	Disability Studies in Nederland

PCO, VU University Medical Center, Amsterdam

Irene van Baardwijk, PAOG Course & Congress Organisation
Patricia de Waal, PAOG Course & Congress Organisation

Amsterdam

The Dutch capital has been – through the centuries – a renowned cultural, scientific and commercial center and has always been characterized by its open mind and flexibility. It cherishes a long tradition of unrestricted exchange of ideas. Although Amsterdam is one of Europe's leading capitals, it still has the charm of a village. No other European city can rival Amsterdam's 7.000 historic buildings, some of which date back to the 14th century. The well-known symmetrical rings of canals with over 1.000 bridges summon up visions of Holland's Golden Age. Amsterdam has a dazzling array of cultural attractions with something for everyone.

There are 42 museums, including the Rijksmuseum, the Van Gogh Museum, the Scheepvaartmuseum (Maritime Museum), and the Anne Frank House. The city is also the home of the internationally acclaimed Royal Concertgebouw Orchestra, the Dutch National Ballet and the Dutch Opera.

Moreover, the Dutch are multilingual which makes getting around so much easier. Amsterdam will welcome you warmly and you will feel at home in one of the most interesting cities of Europe.

Venues

VU University Amsterdam

Plenary sessions

All plenary sessions will be held at the Auditorium on the 1st floor of the Main Building of the VU University Amsterdam. The poster area as well as the coffee, tea and lunch breaks are located in the immediate vicinity of the Auditorium.

Parallel sessions

On Friday, the concurrent sessions will be held in the Auditorium and in several lecture rooms located in a building opposite the Main Building, called the W&N building at the 6th floor.

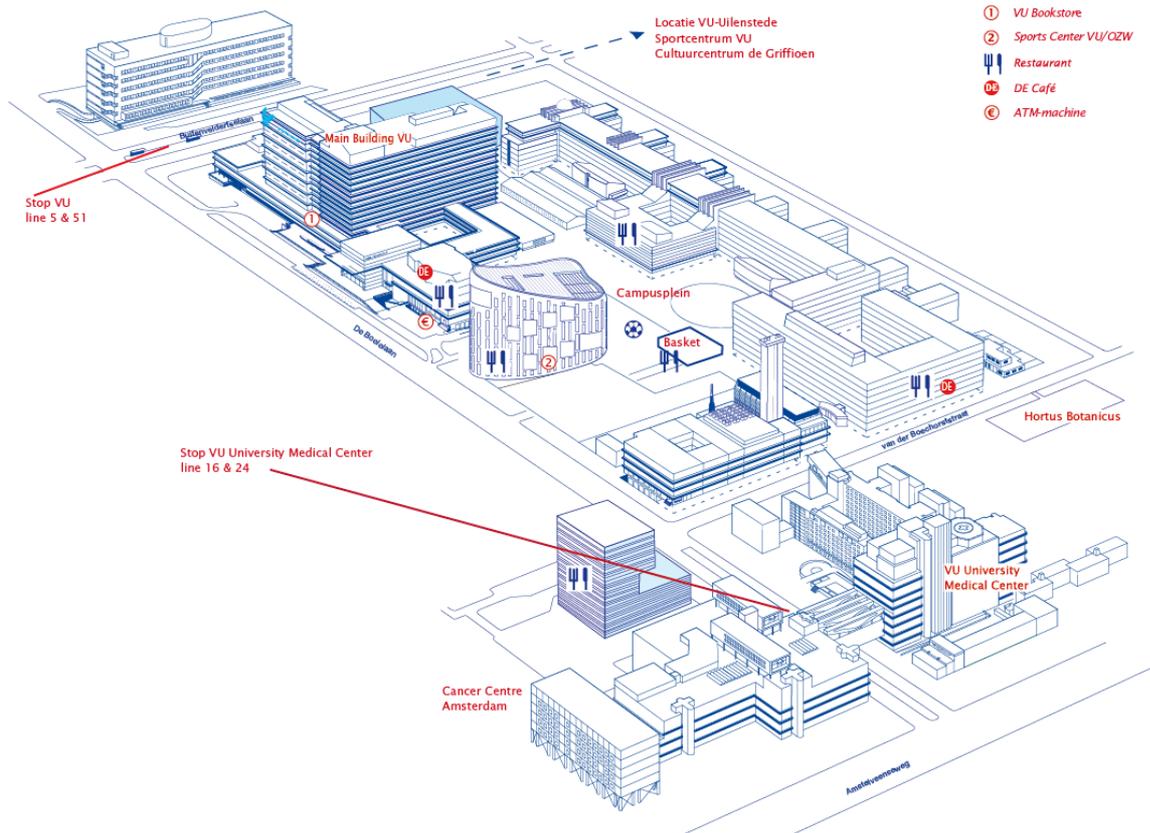
On Saturday, the concurrent sessions will be held in the Auditorium and in a building next to the Main Building, called the Bellevue. In the programme at page 11-17 the lecture rooms are indicated.

Please be informed that there is a maximum capacity of 40 persons on Friday in the lecture rooms of the W&N Building and on Saturday a maximum capacity of 32 persons in the Bellevue Building. All others we would like to direct to the lecture which will be held in the Auditorium.

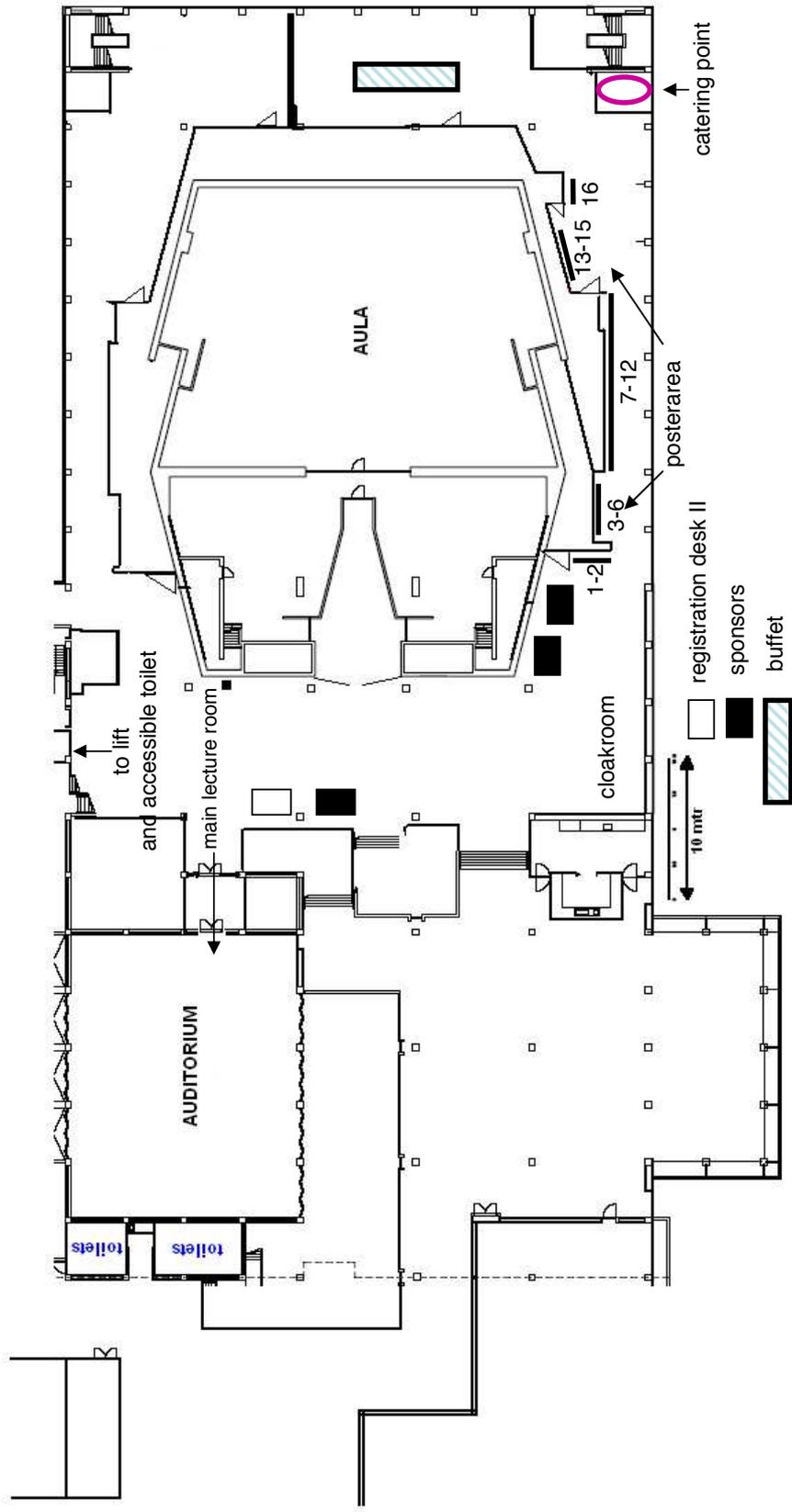
Address:

VU University Amsterdam
De Boelelaan 1105
1081 HV Amsterdam
The Netherlands

Floor plan VU University Amsterdam and VU University Medical Center



Floor plan Auditorium and posterarea



Registration

Opening hours registration desk

Venue: VU University Amsterdam	– Thursday, December 2	16:00-19:00 hrs (ground floor)
	– Friday, December 3	08:30-17:30 hrs (first floor)
	– Saturday, December 4	08.30-14.00 hrs (first floor)

Registration fees

The conference fee includes:

- welcome reception on Thursday, December 2
- programme & abstract book
- admission to all sessions (in case of a day ticket only on the day you attend)
- coffee, tea and lunch during conference hours (in case of a day ticket only on the day you attend)

Contact details during meeting hours:

Phone: +31 (0)20 598 5793

Fax: +31 (0)20 598 5727

Programme information and instructions

Accreditation

Accreditation for Dutch participants

Applications for credits have been sent to:

- FGzP (Federatie voor Gezondheidszorgpsychologen)

Certificate of attendance

A certificate of attendance may be collected at the registration desk upon departure when the evaluation form has been completed. Delegates should sign a presentation list daily available at the registration desk, please indicate your BIG-number on this list.

Instructions for oral presenters

The following audiovisual equipment will be available in the lecture rooms: laptop, beamer and laserpointer.

When you bring a PowerPoint presentation, be sure to save it with the option “include fonts” selected, otherwise there’s a considerable chance that the layout of your slides will appear differently from where you created them. Please bring a Windows compatible back-up file to the conference and check whether your presentation works in PowerPoint.

Please make sure that at least 15 minutes before the start of the session, your presentation is uploaded in the right lecture rooms which is indicated in this programme, see pages 11-17.

Instructions for poster presenters

All posters will be on display for the full duration of the conference. The posters should be mounted on the allocated boards in the poster area on Thursday, December 2 from 16.00 till 19.00 hrs and from Friday, December 3 from 08:30 till 09:30 hrs (fixing material will be provided).

The poster sessions will take place on Friday, December 3, from 12:30 – 13:15 hrs for odd numbers and from 13.15 – 14.00 hrs for even numbers. We expect poster presenters to be present at these times.

Posters should be removed from 11:30 till 14:00 hrs on Saturday, December 4. Unclaimed posters will be discarded after this time.

Social programme

You will have several opportunities to meet your colleagues and friends in informal settings at the conference and at the social events. The social programme includes the following items:

Thursday, December 2

21:00-21:30 hrs: Welcome Reception sponsored by the City of Amsterdam

An informal welcome reception with drinks and some snacks will be held at the Main Building in the immediate vicinity of the Auditorium. We would like to thank the City of Amsterdam for sponsoring this function.

Friday, December 3

19:00-21:30 hrs: Conference dinner at The Basket

(Tickets can be bought (upon availability) at the registration desk for € 40)

VU University Amsterdam has its own 'Grand Café' on campus: The Basket (located just off the central square).

"Art and Activism in the Disability Discours" by Mat Fraser and Ine Gevers

During the conference dinner Mat Fraser and Ine Gevers will perform an inspiring presentation in three parts, accompanying starter, main course and dessert.

Ine Gevers is artistic director of Niet Normaal - Difference on Display. She is also a writer and activist. Mat Fraser is a writer, actor, performer of acts of cabaret and an activist. He recently visited The Netherlands with the show: "The Freak and the Showgirl".

General information

Badges

Upon registration you will receive a personal badge and delegate information. You are kindly requested to wear this badge at all times during the conference. Access to all sessions and the complimentary coffee, tea and lunch will only be provided to participants wearing their badge.

Cloakroom facilities

A cloakroom is situated on the first floor close to the Auditorium. The cloakroom is free of charge, please be informed that this is NOT guarded during conference hours. The organizers cannot accept any liability for loss or damage to property.

Currency and banking

The currency in The Netherlands is the Euro (€). Visa, Mastercard and American Express are accepted at the registration desk. Usually all major credit cards are accepted for payments in hotels, restaurants and shops. An ATM machine is located right outside the Main Building. Banks in Amsterdam are open from 10.00 to 16.00 hrs (Monday to Friday).

Accessible toilet

At the Main Building the accessible toilet is situated on the ground floor.

Disclaimer

All best endeavors will be made to present the programme as printed. However, the Local Organising Committee and PAOG Course and Congress Organisation reserve the right to alter or cancel, without prior notice any arrangements, plans or other items relating directly or indirectly to the meeting for any cause beyond its reasonable control.

Furthermore The Local Organising Committee, the VU University Amsterdam and PAOG Course and Congress Organisation accept no liability for personal injuries or loss, of any nature whatsoever, or loss or damage to property either during or as a result of the conference.

Electricity

The voltage in The Netherlands is 220-240 Volts.

Evaluation Form

An evaluation form is included in the conference satchel. You are kindly requested to complete this form and to deposit it at the general registration desk upon departure. When we have received your evaluation form you will get a certificate of attendance.

First aid

If any delegate requires first aid, please contact the main reception desk of the VU University Amsterdam which is located on the ground floor. Their staff is trained to provide first aid and know how to contact if further medical assistance is needed.

Language

The official language of the symposium is English. No translation arrangements will be made.

Local transport

Amsterdam is a very compact city where your destination will usually not be at a great distance. The city is therefore ideal for getting around by foot, bicycle or public transport. Amsterdam has a very dense public transport system and tram, metro or bus stops are usually around the corner. Please note that the metro is accessible for wheelchairs but not all trams and busses are!

Cars are less suited for getting around in Amsterdam because the city can be considered as car-unfriendly. Parking has to be paid for in almost the entire city and the rates can be substantial.

Lost property

Enquiries regarding items lost or found can be made at the registration desk or at the main reception desk of the VU University Amsterdam.

Messages

A message board is located close to the registration desk. Please check for messages regularly and contact the symposium staff at the desk to collect your messages.

Photocopies

A photocopy service is located in the basement of the Main Building, one floor below the registration desk. Charges are to be paid in cash.

Restaurant

A restaurant is located in the basement where you can get hot meals at a reasonable price till 19.00 hrs.

Shop

The VU University Bookshop is located near the main entrance (opened weekdays 09.00 – 19.00 hrs and Saturdays 10.00 – 15.30 hrs). A shop selling magazines and office supplies is housed in the basement of the Main Building (only opened on weekdays).

Smoking

In all public areas, smoking is prohibited by law. Smoking is only permitted in a few designated areas outside the university.

Taxis

Taxis can be ordered at the main reception desk of the VU University located on the ground floor. To order taxis for disabled people we would like to direct you to the registration desk.

Tipping

Service is always included. However, it is customary to tip in restaurants in bars, and when paying for taxis. As a general rule tipping between 5-10% should be adequate.

Please note: Mobile phones must be switched off during lectures.

Programme

Thursday, December 2

Chair: Anton Westerlaken

- 16.00 – 19.00 hrs** **Registration**
- 18.30 – 19.00 hrs** ***Welcome coffee and tea***
- 19.00 – 20.00 hrs** **Opening conference**
Secretary of State & Sam Galesloot
Auditorium
- 20.00 – 21.00 hrs** **Public lecture / Keynote I**
“Differing ways to think about the controversial term “quality of life”.”
Adrienne Asch
Auditorium
- 21.00 – 21.30 hrs** ***Reception***

Friday, December 3

Chair: Alice Schippers

- 09.00 – 09.30 hrs** **Registration**
- 09.30 – 10.30 hrs** **Keynote lecture II**
“The End of Normal: Diversity and Disability”
Lennard Davis
Auditorium
- 10.30 – 11.00 hrs** ***Coffee & tea break***
- 11.00 – 12.00 hrs** **Keynote lecture III**
“Exploring disabled experience: deviant, disadvantaged, diverse?”
Jackie Leach Scully
Auditorium
- 12.00 – 13.30 hrs** ***Lunch & Poster sessions***
Odd numbers from 12.00-12.45 hrs
Even numbers from 12.45-13.30 hrs

Poster presentations:

1. Mariska de Swart: "Project Pink Wheels - recognizing capability: disabled homosexuals"
2. Laura Fontil: "Children with autism and their transition Preschool to Kindergarten: A Multicultural Approach"
3. Erin Sulla: "Measuring children's attitudes towards disability after one year in a reverse integrated setting."
4. Cindy de Clerck: "Action research and quality of life: People with an intellectual disability as co-researchers."
5. Janneke Hatzman: "Objective and subjective disability characteristics related to subjective well-being in young adults with a visual impairment - a longitudinal design."
6. Marcia Lever: "Self perception of adolescents with mild to borderline intellectual disabilities. A qualitative study."
7. Kameswararao Chiruvolu: "On Tools Techniques and Technologies to compensate functional impairments."
8. David S. Hidajattoelah: "Discussing jobs in the Netherlands for Experts by Experience."
9. Abdulaziz A. Al-Mohisen
10. Nuno Rocha: "Self-determination of homeless people living in a shelter in the metropolitan area of Oporto, Portugal."
11. Nuno Rocha: "Social cognition and functioning in schizophrenia: an exploratory study with Portuguese outpatients."
12. Jo Lebeer: Sophie's choice: "whose life needs to be preserved at its beginning? Ethical paradoxes in ante- & perinatal decision making."
13. Steinmetz de Compaan, Liesbeth de Ree en Eva Wiersma: "Diversity in achieving Quality of Life."
14. Heliomare, Judith van Velzen: "Return to work after acquired brain injury: What did people experience?"
15. Pameijer, Joke Ellenkamp: "Pameijer with 'Circus Pameijer'."
16. Vilans, Ineke Aufderhaar

13.30 – 14.30 hrs

Concurrent sessions I

A. To be or not to be

Chair: Ingrid Baart

WN-C659

1. Marcel Broesterhuizen "Cochlear implantation and genetic research; blessing or curse?"
2. Karen Mogendorff "What using embodied knowledge does to the quality of life of the researcher: personal reflections."
3. Jenny Boumans en Marianne van Bakel "A reflection on empowerment: insights from theory, literature and HEE* practice."

B. What distinguishes disability studies?

Chair: Marja Hodes

WN-C669

1. Jeanette Pols "About modern patients, medical knowledge and the place of experience."
2. Lieke van Heumen "Disability Studies and aging"
3. Joan van Ee "Sharing the loop: A grounded approach to relating to and through medication"

C. How does disability experience affect quality of life?

Chair: Alice Schippers

Auditorium

1. Wanda Katja Liebermann "Make-believe streets and citizens: Building Dutch and disabled in Het Dorp, the Netherlands".
2. Silke Hoppe "Does disability affect quality of life?"
3. Dick Willems "Quality of life: measure or listen"

D. Multi Cultural Perspectives on Quality of Life

Chair: Wim van Brakel

WN-F607

1. Jos Philips "Diversity in quality of life among disabled people and standardized approaches."
2. Walton O. Schalick "The Quality of Quality of life: a history of bureaucratic assessments of western disabled children, 1802-1970."
3. Joachim Gerich "The impact of social capital on quality of life for elder deaf persons."

14.45 – 15.45 hrs

Concurrent sessions II

C1. How does disability experience affect quality of life?

Chair: Marja Hodes

Auditorium

1. Dorien Veltens “Existential wellbeing and quality of life.”
2. Julia Bahner “Disabled sexuality? A qualitative study on physically disabled people and sexuality issues with personal assistance services.”
3. Cretien van Campen “Inequity in subjective well-being of people with chronic disabilities in 21 European countries.”

C2. How does disability experience affect quality of life?

Chair: Alice Schippers

WN-C659

1. Carla G.L. van Deursen, Anneke M. van der Giezen “Trends in employment of people with disabilities in The Netherlands.”
2. Annette Hendriks “Participation with acquired brain injury in contemporary society: ‘You have to learn how to deal’.”
3. Rick Kwekkeboom “Happy to be taking part? Predicting the relationship between social participation and quality of life.”

D. Multi Cultural Perspectives on Quality of Life

Chair: Wim van Brakel

WN-C669

1. Frank Renders “Quality of life, intellectual disability and the erasure of cultural differences.”
2. Silatham Sermittirong “Quality of life in Thai perspective.”
3. Corline Brouwers “Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in South-East Nepal.”

15.45 – 16.15 hrs

Coffee & tea break

16.15 – 17.15 hrs

Concurrent sessions III

A. To be or not to be

Chair: Ingrid Baart

WN-C659

1. Lineke van Hal “Beyond vocational rehabilitation as skills training: return-to-work as an identity issue.”
2. Mariët Veen “Being an entrepreneur, having an impairment.”
3. Brigitte van Lierop “Definitions of Disability and its implications”

C. How does disability experience affect quality of life?

Chair: Alice Schippers

Auditorium

1. Carolien Hermans “Dance education for children with special needs: kinaesthetic empathy and mirroring techniques.”
2. Miranda D’Amico “Applying quality of life assessment in a therapeutic intervention for adults with developmental disabilities.”
3. Siegfried Saerberg “Ohrenblicke - making oneself heard by making radio as a leisure activity of blind people.”

D. Multi Cultural Perspectives on Quality of Life

Chair: Wim van Brakel

WN-C669

1. Mimi M. Lusli “Diversity and Quality of Life of Persons with Disabilities (PwD) in Indonesia.”
2. Angela Dede Williams “Quality of Life of Persons with Disabilities in Ghana”
3. Bregt Lameris “Becoming metaphors - on the interrelationship between 19th century psychiatric photography and the shaping of identities.

17.30 – 18.30 hrs

Cultural programme

“Signed poetry and the power of visual communication”

Anja Hiddinga

Auditorium

18.30 – 21.00 hrs

Conference dinner

“Art and Activism in the Disability Discourse”

Mat Fraser & Ine Gevers

The Basket

Saturday, December 4

Chair: Anton Westerlaken

- 09.00 – 10.00 hrs** **Keynote lecture IV**
“Quality of life: reflections from evaluation of community-based rehabilitation projects in India and China”
Maya Thomas
Auditorium
- 10.00 – 10.30 hrs** **Announcement disability journal**
Maya Thomas and Wim van Brakel
Auditorium
- 10.30 – 11.00 hrs** **Coffee & tea break**
- 11.00 – 12.00 hrs** **Concurrent sessions IV**
- A. To be or not to be**
Chair: Ingrid Baart
BV-0H19
1. Henny Mulders “Being at work - how to include people with disabilities in regular work organizations”
 2. Jo Lebeer “Dynamic and functional assessment for a developmental and inclusive perspective.”
 3. Marco Fuscaldo “The capability perspective of impairment and disability: an application among elderly people in Italy.”
- B. What distinguishes disability studies?**
Chair: Geert Van Hove
BV-0H20
1. Jean-Francois Trani, Federica di Marcantonio “Conceptual comparison of methodological issues in assessing disabled functioning and capabilities.”
 2. Paul van Trigt “The blind, the sixties and religious care.”
 3. Helene Combrinck “Not good enough? Examining the 'Quality of life' of persons with disabilities in South Africa.”

C. How does disability experience affect quality of life?

Chair: Alice Schippers

Auditorium

1. Thiandi M.A. Grooff "ActNormal: a personal account on common views on "normality" and "disability" and the essential need to belong and be different at the same time."
2. Xavier Moonen "Towards a participatory culture: children or adult clients as co-researchers in a residential care institution for people with intellectual disabilities and significant behaviour problems."
3. Sophia Kramer "Hearing ability and its association with psychosocial health & need for recovery after work in adults aged 18-70 years."

D. Multi Cultural Perspectives on Quality of Life

Chair: Wim van Brakel

BV-0H21

1. Patrick de Vlieger "Making sure that this does not happen again": Women's leadership as an Actor in Special Olympics networking in Paraguay.
2. Benjamin Mayer-Foulkes "On how blind photographers suggest a fourth way of inhabiting and approaching "disability"."
3. Beatriz Miranda Galorza "Getting to know you....: disabled people and the politics of friendship in Ecuador."

12.00 – 13.00 hrs

Keynote lecture V
"Quality and narrative"
Hans Reinders
Auditorium

13.00 – 14.00 hrs

Lunch and Farewell

Abstracts keynote presentations

K - 01

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

Dr. Adrienne Asch

Center for Ethics, Yeshiva University, New York, United States

Many people in the field of Disability Studies, and many disability advocates, understandably fear that “quality of life” judgments made by people unfamiliar with the lives of those with disabilities have been and will continue to be biased against them, as demonstrated by dominant bioethical statements about starting or continuing lives that will include disability. Such negative perceptions can adversely affect access to societal resources and life outcomes. Thus, societal beliefs about how a person’s disability leads to a reduced quality of life can be used as a self-fulfilling prophecy, to guarantee just such a result. But when viewed from the perspective of people with disabilities, quality of life ideas can be useful guides to assessing whether a person with a disability is living well or poorly. I will argue that the components that go into assessing quality of life for the general population can be applied to people with disabilities and that if they are so applied, we can get useful information to help people with disabilities improve their lives. Such quality of life assessments can demonstrate what society needs to do to maximize the opportunities for people with disabilities to lead rewarding lives. The talk will include examples of ways that nondisabled and disabled scholars assess how congenital or acquired sensory, physical, or cognitive disabilities affect an individual’s life. Although I will suggest that disability may not be exactly like such characteristics as race or gender in having no negative life impact apart from adverse discrimination, I will argue that nearly all of the presumed negative facets of life with disability can be ameliorated by reformed societal practices.

K - 02

“The End of Normal: Diversity and Disability”

Prof. Lennard J. Davis

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

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

K - 03

“Exploring disabled experience: deviant, disadvantaged, diverse?”

Jackie Leach Scully

Newcastle University, Newcastle upon Tyne, Britain

In this presentation I will address 'the difference a difference makes' to understanding quality of life -- especially when that difference is a disability. For the most part, disability is seen as a deviation from the norm of a good life, and therefore as a difference that necessarily means a reduction in quality of life. I will suggest that greater willingness to explore the diversity of disabled people's real life experiences will challenge our notions of what constitutes, or can constitute a good life. Although many impairments unarguably do entail disadvantage and suffering, in at least some cases this could be minimised through social changes, while in others, physical or mental difference may better be reconceptualised as diversity in the possible ways of being in the world. But to do this while also doing justice to the real disadvantage and suffering experienced by many disabled people requires appropriate research methodologies and epistemic humility in the face of unfamiliar narratives, norms and priorities.

K - 04

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

Dr. Maya Thomas

Asia Pacific Disability Rehabilitation Journal, Bangalore, India

Theme

Multi Cultural Perspectives on Quality of Life

Aim

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

Methods

The evaluation findings used for the purpose of this paper were based on 2 evaluations led by the author: a community mental health project implemented by a non-governmental organisation in India; and a provincial CBR project implemented by a semi-governmental organisation in China. Both evaluations assessed relevance, effectiveness and sustainability of the projects. In both evaluations, voices and lived experiences of persons with disabilities were documented.

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

Results

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

Conclusions

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

K - 05

“Quality and narrative”

Hans Reinders

VU University Amsterdam, Amsterdam, The Netherlands

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

Abstracts poster presentations

P - 01

Project Pink Wheels – *recognizing capability: disabled homosexuals.*

Mariska de Swart

COC Nederland, SaMar counseling and advisory bureau

*“Whether or not to participate in the Canal Parade? Which boat to join?
Do I belong on the women’s boat, or on the boat of the police force
where I work, or on the boat representing homosexuals with a disability?”
Speaking is Ellen, a lesbian woman with a visual restriction,
who is, as she rightly observes, much more than those two things.
When you are a homosexual man or woman with a disability,
it feels like you have to choose which box to put yourself in.
But ... in each you won’t fit.
Disabled gays are on the side-line, in both gay- and disability movement.*

Project Pink Wheels is a three-year program for and by people (man, woman or transgender) with gay or bisexual feelings *and* a physical, visual, or auditory handicap or restrictive chronic disorder.

The project is aimed at *empowerment, representation and visibility and protecting the interests of gays with a disability.*

In this project several subprojects will be done:

- Empowerment will be done by setting up a web community where disabled gays can meet others like them. Followed by several energetic optimistic workshops about dealing with both minority’s. ‘How do others do?’. Role-models are important in these sub-projects.
- Giving “a face and a voice” in interview/portraits and in a photo-exhibition. Joining the GayPride Canalparade with broad media-activities is important to inform the gay- and disability movement and out standers about the existence and special needs of handicapped gays.
- In ‘protecting the interests’ we are going busy with accessibility of the gay movement and –scene. Introducing gay-friendly logo’s in healthcare and advice institutes how to deal with this subject and gay-patients..
A symposium about homosexuality and disability will be held in the last year. That time we will evaluate and discuss next steps.

Goal: empower the handicapped gays so they dare to ‘stand up’, showing themselves, being proud, and give them hands to fight and deal with the special needs they have, so they will be seen and be welcomed in the gay- and disability movement and in healthcare.

Pink Wheels: www.rozewielen.coc.nl

P - 02

Children with Autism and Their Transition Preschool to Kindergarten: A Multicultural Approach

Laura Fontil and Harriet Petrakos

Concordia University, Montreal, Canada

Aim

Research on transition to school has noted that the implementation of appropriate transition practices can ease the transition to school for children (e.g. Dockett & Perry, 2003). Less is known about the transition to school for children with special needs in the Canadian population (Janus, 2004) and furthermore research on minorities with disabilities' transition to school is also lacking (Odom, 2000). Taken together, it is evident that there is a need for research on transition to school for minorities with disabilities.

The purpose of this study will be to explore families of children with Autism Spectrum Disorder's (ASD) experiences with the transition from preschool to kindergarten while using Rimm-Kaufman and Pianta's (2001) Developmental Model of Transition as a framework. Further this study is also interested in comparing the experiences of Canadian born and immigrant families.

Methods

Ten children with an Autism Spectrum Disorder (5 Canadian born, 5 immigrant) beginning to make the transition from exclusive preschool care to inclusive kindergarten care will be investigated in this qualitative study. Transition experiences will be discerned with the use of semi-structured interviews. Parent perceived stress levels will be assessed with the IOF1. The MPOC2 will be used to understand parents' experiences with community resources. Children's adaptive behavioural level and social competence will be determined with the ABAS3 and the SSRS4.

Results

Due to the exploratory nature of this study expectations are limited. In our preliminary results we expect that immigrant families are expected to experience more barriers in successful transition and subsequently these children will perform poorer on social competence measures. Some of the themes that have emerged in past research on inclusion and diversity have included: belonging and membership, language issues, and competing values (Hanson, et al., 1998) to name a few. Our goal is to ascertain whether these issues (or other issues) present themselves with our population of families who are making an important transition.

Conclusions

The preschool years are incredibly important for all children, as it is at this formative stage in development that essential skills for successful school and life transitions are developed (Hanson et al., 1997). With more knowledge effective transition practices can later be developed to help ease this difficult transition for children in need.

P - 03

Measuring Children's Attitudes Towards Disability After One Year in a Reverse Integrated Setting

Erin Sulla

Concordia University

This project aims to examine whether or not there is a correlation between the attitudes of typically developing elementary school children towards children with disabilities, and the actual quality of their social interactions with children with various disabilities. By adopting a mixed-methods approach, the present study is an attempt to understand, and follow, typically developing children's attitudes or "planned behaviours," as well as their "actual behaviours" towards their peers with disabilities, in a Reverse Integration program at a school for children with special needs (12 children, both male and female, ages 4-10). The data concerning children's attitudes towards their disability have been collected using Favazza and Odom's (1999) Acceptance Scale for Kindergartener, Revised (ASK-R). Additionally, each reverse integrated child is being observed during recess. During the observation, the frequency of interactions between children with and without disabilities, as well as the quality of these interactions (positive or negative, the role of the interaction and the purpose), is being noted using the Educational Assessment of Social Interaction, modified (EASI-2). Both attitudes and interactions will be compared to see if there is an interaction. From the data that has been collected, there is an interaction. Additionally, an interview with each child will reveal further qualitative data. It is imperative that researchers try to understand attitudes and natural behaviours towards their peers with disabilities in order to understand how to make inclusion a more positive experience for both children with and without disabilities.

P - 04

Action research and quality of life: People with an intellectual disability as co-researchers

Cindy De Clerck

Aim

We aimed to develop a research methodology to study QoL from the perspective of a person with an intellectual disability in a residential setting.

Method

We used the method of participatory action research to address information. This method brings the research as close to the research subjects as possible and empowers them to collaborate to the research as active as possible.

Results

Through this method we got a inside view onb how people in institutions view their quality of life and what they want to do about/with it. On the other hand, the method shows us a new way of involving people with an intellectual disability into the research.

Conclusions

Not only is QoL a concept that can be made accessible to people with an intellectual disability, it is also possible to empower these people to work close on the subject. Furthermore, QoL is an individual concept, that has a different definition regarding to who is actually addressed. The method of action research can help professionals to get a better view on the situation, and can help clients to get more empowered.

P - 05

Objective and subjective disability characteristics related to subjective well-being in young adults with a visual impairment – a longitudinal design

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Department of clinical child and family studies, Faculty of Psychology and Education, VU University Amsterdam.

Aim

To assess the relation between objective and subjective disability characteristics in adolescence and young adulthood and subjective well-being (SWB) in young adults with a visual impairment.

Methods

Participants with a visual impairment were interviewed in three waves, in 1997, 2005 and 2010: from adolescence to adulthood. Data about SWB and disability characteristics were collected using a structured interview. The dependent variable SWB was measured with the Cantrill scale for Subjective Well-being (1965). Objective disability characteristics were measured with the Functional Vision Scale adapted from Weiner (1991), and a single question asking if the disability was stable, deteriorating or improving. Subjective disability characteristics were measured with a subscale from the Nottingham adjustment scale (Dodds et al, 1994) assessing acceptance of the impairment, and a newly developed scale to measure perceived influence of the disability in daily life.

Results

Data from the last wave are not yet complete, but will be presented in December 2010. Data from the second wave show a significant association between subjective well-being and acceptance of the impairment ($\beta=.38$, $t=2.955$). Objective disability characteristics were not significantly related to SWB.

Discussion

Although results are not complete yet, data from the first two waves suggest a more significant role for subjective disability characteristics in explaining SWB, than for objective characteristics. This contrasts the widespread opinion that for instance 'severity' of the disability (e.g. blind, severe and moderate low vision) is an – or the most- important factor in explaining SWB. The way people perceive their disability seems more predictive. This may direct interventions for children and adolescents with a visual impairment.

P- 06

Self perception of adolescents with mild to borderline intellectual disabilities. A qualitative study.

Author(s)

Marcia Lever, Maroesjka van Nieuwenhijzen

- Expertisecentre William Schrikker Group

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Aim

Adolescents with mild to borderline intellectual disabilities (MBID) tend to overestimate their skills and the development of accurate self-perception is delayed. There are indications that relationships exist between self-perception and behavior. According to the social information-processing theory (SIP; Crick & Dodge, 1994) social experiences and self-perception form a 'database', which influences the different social information processes: encoding and interpretation of information from social situations, goal setting, response generation, evaluation and response selection for enactment. Research has shown that children with MBID have difficulties with SIP, and that inadequate SIP can explain their behavioral- and social adaptation problems (Van Nieuwenhijzen et al., 2006). However, there is a lack of understanding of the database and the way adolescents with MBID think about their disability. The aim of this research is to examine the database from the adolescent's perspective.

Method

In this qualitative research adolescents with MBID will be asked about the way in which they experience their disability. Fifteen adolescents aged 14 – 18 will be interviewed by means of a list of topics, based on the International Classification of Functioning, Disability and Health (ICF). Topics will focus on body structure and functions, activities, participation, environmental factors and personal factors.

Results

An attempt is made to extract themes or styles of self-perception by analysing the transcripts. Themes will be presented to a focus group consisting of adults with MBID to obtain better comprehension of the themes. Results will be used to construct an instrument which can be used in a larger study to examine the connection between self-perception and SIP.

Conclusion

A positive and realistic self-image improves quality of life of adolescents with MBID. One can assume that the outcome will contribute to a stronger connection between the adolescent and the social worker. Also, in-depth understanding in the subjective perception of the adolescents is expected, from which insight can be gained in the relation between self-perception and SIP.

P - 07**On Tools Techniques and Technologies to compensate functional impairments**

Kameswararao Chiruvolu

Andhra Pradesh, India

Aim

To analyze functional requirements of an individual regarding mobility, agility and language skills. To adopt appropriate tools, techniques and technologies to compensate impairments if any.

Method

Several key functional requirements of a human being like ability to sit, stand, walk, speak, conceptualize, comprehend, memorize, read text and write text are analyzed. Analysis is done from the perspective of improving the quality of life in spite of constraints in performing these functions. Existing tools, techniques or technologies are studied, analyzed and adopted to suite the individual needs. Three types of essential functions namely mobility, agility and language skills are considered in this work. Experimentation is done with the help of persons having impairments in one or more functions of one or more types. Based on the response from the persons with impairment, tools, techniques and technologies are further refined. If there is shortfall in the functionality of identified tools or techniques necessary modification or development of appropriate tools is attempted.

Results

Mobility:-several cerebral palsy children have shown progress comparable to a new born baby regarding major milestones in mobility aspects like sitting, crawling and standing on using vibration therapy. Vibration therapy is based on fitness gadgets. Agility:-Interactive edutainment computer programs available in the free software domain have been successfully used to address sensory integration, thinking, reasoning and working memory aspects of persons with less agility or mental retardation. Language skills:-Computer programs available in free software domain are used. Recording and play back of the sounds, words with necessary amplification has a positive impact on the persons with speech impairment. Another computer program is used for writing text in vernacular language using the standard computer keyboard. Persons who had little control over the shape, size and orientation of characters they write have been successful in keying in words.

Conclusions

Present work covering about 50 persons in the age group 4 years to 40 years is done to ascertain the validity of the approach. There is a need to carry out extensive study in a systematic method to establish the approach.

P - 08

Discussing jobs in the Netherlands for Experts by Experience

Harrie P.M. van Haaster, David S. Hidajattoellah

Instituut voor Gebruikersparticipatie en Beleid,

program: Expertise by experience

project: implementing expertise by experience in a mental health institute

Aim of the project is to define tasks, competences and indications of levels of competences to be acquired for getting a job as an expert by experience in mental health care or in care for persons with addiction problems. The research was conducted in a big mental health institution in the Netherlands. The project was multitrait method with a mixed actions research design. It contained 1) study of literature and other documents, 2) interviews with users, 3) a focus meeting among experts by experience and 4) a concept mapping procedure.

Results describe both the enormous impact in the field of mental health care when experts by experience are seen as a valuable addition and the problems and resistances this meets in the institutions.

Expertise by experience leads to a fundamental different view on psychiatric problems and diagnoses. It shows how much bad labelling and stigmatization there is in a lot of psychiatric practices. Practices of professional and non professional experts by experience and/or peer experts encompass for example self help groups, working with self determinacy, independent living, self assessments, social support systems and peer counselling. The conclusions of the project are 1) job descriptions, 2) descriptions of competences and indications of competence levels and 3) recommendations for education of experts by experience and 4) recommendations about institutional conditions that are necessary to successfully involve experts by experience in treatment programs.

P - 09

Abdulaziz A. Al-Mohisen

P - 10

Self-determination of homeless people living in a shelter in the metropolitan area of Oporto, Portugal

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Instituto Politécnico do Porto: Escola Superior de Tecnologia da Saúde

Some of the components that compose self-determined behavior, such as decision making, problem solving, goal setting and positive attributions of efficacy seem to be affected in homeless people. This leads us to believe that homeless people have lower levels of self-determination. However, to the best of our knowledge, this subject was not explored in previous work.

The goal of this study is to compare the levels of self-determination between a group of homeless people living in a temporary shelter and a group of domiciled persons. Self-determination was assessed using "The Arc's Self-Determination Scale" and differences between groups were tested using the *t-student* test. This scale was administered to a total of 30 participants living in a shelter and a group of persons living independently, both in the metropolitan area of Oporto.

Results show statistically significant differences in self-determination between the groups ($p < 0.001$), as well as in three of its domains, including, self-regulation, psychological empowerment and self-realization. We conclude that the group of homeless people has significantly lower levels of selfdetermination, particularly in the subdomain of cognitive interpersonal problem-solving.

With these findings, we expect to provide a better identification and understanding of the problems of homeless people.

P - 11

Social cognition and functioning in schizophrenia: an exploratory study with Portuguese outpatients

Nuno Rocha^{1,2}, Cristina Queirós², Ana Gouveia¹, Andreia Silva¹, Cláudia Soares¹, Ana Ribeiro Bravo¹

1 – Porto Polytechnic Institute – Health School

2 – University of Porto: Faculty of Psychology and Educational Sciences

Schizophrenia is a mental illness associated with impaired social cognition. There is a growing body of evidence suggesting that deficits in social cognition contribute to disability and poor quality of life. The aim of the present study was to examine the associations between several domains of social cognition and psychosocial functioning in schizophrenia. The sample consisted of 30 Portuguese outpatients with a diagnosis of schizophrenia. The participants completed an assessment procedure that included measures of emotion recognition (Facial Emotion Identification Test), theory of mind (Corcoran Hinting Task), attributional style (Ambiguous Intentions Hostility Questionnaire), jumping to conclusions (Fish Task), managing emotions (MSCEIT-Managing Emotions Branch), social perception (Social Perception Scale) and executive functioning and processing speed (Trail Making Test A and B). Psychosocial function was assessed with the Portuguese version of the Life Skills Profile. Several social cognitive measures were correlated with the Life Skills Profile domains related to communication ability and social interaction. These results suggest an important contribution of social cognition in the psychosocial functioning of people with schizophrenia and encourage the development of specific programs intended to remediate impairments in social cognition to improve better functional outcomes.

Sophie's choice: whose life needs to be preserved at its beginning? Ethical paradoxes in ante- & perinatal decision making

Jo Lebeer

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

Aim

Disability advocates increasingly worry about some trends in decision making during pregnancy or around birth, regarding who is given the right to live: the (in the West) widespread and increasing use of prenatal diagnosis and the discussions on life-saving measures for newborns born with a condition leading to disability. For disability rights advocates, these two trends signify a rejection of their value and right to existence. These arguments are usually rebutted in medical journals. The aim of this research is to analyze the ethical paradox of selective TOP for viable disability, versus massive efforts to preserve life in premature newborns, often resulting in major disabilities.

Participants and methods

We did a literature search on the medical state-of-the art of prenatal diagnosis of conditions which might lead to a possible disability. We compared numbers of future parents choosing for a TOP in some Western countries (Belgium, the Netherlands, France, Israel) after PND. We looked for data on active and passive ending of life in newborns with a disability. We analysed the discourse in various medical (ethical) journals.

Results

In Western countries, a large majority of parents, after prenatal diagnosis of a so-called "malformation" – that is how medical literature describes conditions which possibly lead to a condition of disability - , chooses for termination of pregnancy (TOP). The "seriousness" of the condition is mostly seen as relative. There is controversy in the literature whether there is pressure from the medical staff; they are supposed to advise in a neutral way, but it seems that medical staff takes TOP for granted if there is a malformation. As for newborns, there is a totally different medical attitude towards life-saving measures. Also there is a big difference whether the child is born "healthy" (i.e. without any known condition leading to disability) or with a known "malformation". The "Groningen Protocol", which sets criteria for active ending of life of newborns with serious disability, meets advocates in the medical world but also resistance. We argue that the paradox is based on underlying models of utilitarian ethics and a reductionist view on human functioning, which consider human beings as mainly determined by their biology. We criticize the use of criteria such as "quality of life" and "consciousness" to determine whether individuals with a disability deserve perinatal protection, based on a too negative connotation of disability. Bioethical decision making at the beginning of life is too often based on a medical model of disability, whereas disability organizations situate the main obstacle of disability in discriminatory attitudes by society.

Conclusions

In order to overcome the paradox between the need for non-discriminatory attitudes and therapeutic exaggeration to protect life at all costs, we suggest a non-reductionist bio-psycho-social transpersonal perspective: a combination of a "universal rights" perspective with a concept of "conflict of interests": non-discrimination laws should therefore extend before birth, while at the same time building a disability-friendly culture. The abortion laws of various European countries (France, the Netherlands, , the U.K., Spain and Belgium) would need a reform.

Further research is needed to look at attitudes (projections) of medical staff and future parents on disability and in what way a more positive image could be generated, and how this could be introduced in prenatal counseling. We are currently undertaking such a research project.

P - 13

Diversity in achieving Quality of Life

Liesbeth de Ree and Eva Wiersma

Steinmetz | De Compaan, Rijswijk, The Netherlands

Steinmetz | de Compaan supports people in organizing their own lives, no matter their age or capabilities. A life of their own choosing, according to their own, diverse talents, in short: a life that fits them.

Quality of Life is key, and this cannot be approached in a 'one size fits all' way. It is of the essence that every client has as much control over their life as possible, thus safeguarding their own Quality of Life.

We believe in starting a dialogue with our clients. It is a process of listening and gauging, of assessing and discussing what makes them happy. We keep an open mind and are not afraid to set aside our usual frameworks. This way, we can strive for diverse solutions in achieving Quality of Life.

Quality of Life through daring to dream:

"I'm going to be an artist."

Quality of Life through redefining capabilities:

"I used to be adrift, now I'm a postman's assistant."

Quality of Life through assessing people's roles:

"I'm content to participate by observing from my favourite bench."

Quality of Life through respecting history:

"My neighbourhood is where I live my life."

Quality of Life through fostering coincidence:

"I came here just to have a roof over my head, and now I'm supporting my elderly neighbour."

Return to work after acquired brain injury: What did people experience?

Judith M. van Velzen, Coen A.M. van Bennekom, Max van Dormolen, Judith K. Sluiter, & Monique H.W. Frings-Dresen

Department of Research and Development, and Institute of Vocational Assessment and Education, Heliomare Rehabilitation Centre, Wijk aan Zee, The Netherlands; Academic Medical Center, University of Amsterdam, Department: Coronel Institute of Occupational Health, Amsterdam, The Netherlands

Aim

Employment is one of the most important components of participation for people of working age. It is known that people who are employed report less health service usage, a better sense of wellbeing and a better quality of life than non-employed people. However, return to work (RTW) after a disabling disease like acquired brain injury (ABI) is not always obvious. In order to improve the process of RTW, the aim of the study is to describe the limiting and facilitating factors experienced by adults with moderate to severe ABI during the process of RTW.

Methods

Twelve adults of working age who acquired brain injury three to four years earlier participated in this retrospective, qualitative study. All participants were working before ABI. After injury, six participants were working part-time in paid jobs, two participants were working part-time as volunteers, and three participants were not working at all. Semi-structured interviews were performed to gather information about the experienced limiting and facilitating factors of RTW. The International Classification of Functioning, Disability and Health was used as a theoretical framework for the interviews and the analysis.

Results

From the interviews, it became clear that most participants experienced problems during their process of RTW. The factors that were mentioned were both internal (for example, impairments of the upper or lower extremities) and external to the participants (for example, lack of knowledge and support from employers, colleagues and specialists). The most mentioned limiting factor was tiredness. The most mentioned facilitating factors were the will to return to work, the ongoing recovery and the knowledge and support of the employer, colleagues, occupational physician and occupational specialist.

Conclusions

The process of return to work after ABI turned out to be a complex process in which different aspects were experienced as being important. It is advised to give attention to the recovery opportunities of an individual, to inform the employer, colleagues, occupation physician and the occupational specialist about (the possible consequences of) ABI, and to support people with ABI for long time periods. An important role can be played by the rehabilitation centre.

P - 15

Pameijer with 'Circus Pameijer'

Presentation made by Joke Ellenkamp; general manager Pameijer

Quality of Life concept

The quality of life concept is based on several principles:

1. it is composed of the same factors and relationships for people living on this earth;
2. is experienced when a person's needs are met and when one has the opportunity to enrich one's life in major settings;
3. has both objective and subjective components;
4. is based on individual needs and choices;
5. is a multidimensional construct influenced by personal and environmental factors such as intimate relationships, family life, friendships, work, neighbourhood, status of living, education etc

Important aspects of the quality of life concept have to do with these eight different aspects such as:

1. emotional well being
2. interpersonal relations
3. material well being
4. personal development
5. physical well-being
6. self-determination
7. social inclusion
8. rights

The concept of quality of life has great potential as a synthesis of the purposes pursued in any domain by any person. The concept however is also very useful in service planning and evaluation. Furthermore this concept is of importance in transforming programs and activities for people with mental disabilities. To talk about the quality of life means bringing people to the forefront. It can strengthen people to learn about their own talents. I would like to introduce to you the program we made with 'Circus Pameijer'; a circus in which the talents of people with intellectual disabilities are presented as a means to have a dialogue about important community issues.

Circus Pameijer

We also use the name **Empowerment** that refers to increasing the individual strength of people and groups of people or communities. It often involves the empowered developing confidence in their own capacities. The term empowerment covers a vast landscape of meanings, interpretations, definitions and disciplines ranging from psychology and philosophy to the highly commercialized self-help industry and motivational sciences. Sociological empowerment often addresses members of groups who have been excluded from decision making processes by social, for example discrimination based on disability, [race](#), ethnicity, religion, or gender.

Empowerment gives people a voice to express their feelings and thoughts. Especially for people with an intellectual disability this is of great importance. To include these people into society it is important that they can contribute to society and speak out about things that really are important to them. To support people to do so we started the project 'Circus Pameijer'. In this project people with intellectual disabilities were asked to participate because of their experience in how they are approached in daily life.

We worked together with [Formaat](#). [Formaat](#) is an NGO that uses all kinds of participatory drama techniques to support empowerment of the underprivileged, raise general awareness of human rights and increase dialogue among citizens and/or between citizens and bodies of the government. The method of participative drama is based on working with people who are oppressed, originally created by a Brazilian theatre director called [Augusto Boal](#) during the 1950's and 1960's. Participatory drama can be used to increase interest in local issues and developments, particularly among individuals or target groups that may not engage through traditional methods such as public meetings.

We started with auditions in august 2009. In total 29 people with an intellectual disability came for auditions. The purpose of these auditions was to select 8 capable persons who could do the theatre work and on the other hand gather all kinds of relevant issues to work on in the theatre workshops. The auditions where organised as a workshop and took a whole day.

Subjects that were adressed had to do with: problems with the use of taxi's; sexual abuse; inconveniences with neighbours; becoming a victim; quarrelling with people with whom you share your home; rebuff by support workers and discrimination.

To work out these themes different rehearsals followed in which these themes were worked out. After this period 9 performances where given on different places in the working area of Pameijer. Most of the visitors where clients of support workers. In total 440 visitors came to these different performances. The performances where places in which the artists of 'Circus Pameijer' had a dialogue with all the visitors about the themes they had worked out in the theatre sketches. It was an inspiring way of supporting people with intellectual disabilities by working out themes that have to do with quality of life on different domains. The themes had to do with interpersonal relations, social inclusion, physical well-being, self-determination, emotional well-being, rights and last but not least personal development. This way of working with the stories of the people with an intellectual disability gives them a power that is of great importance for their self-esteem. And all of them liked this way of doing things so much that now we are working out new ways to support them in their further development.

We made a CD of the presentation of the different performances and the discussions we had. After these presentations the group of artists wrote down 28 recommendations that were useful in our organisation. The recommendations were taken seriously and used to improve the way we are supporting people with intellectual disabilities.

To sum up what amazed me: first of all, people are offered **a stage to express themselves**. In the second place, **a social dialogue** takes place between the audience and the stage. In the third place people are **empowered**. Furthermore, I realized participative drama is all about **taking people seriously**, and being taken serious. And above all: not to talk about people but **with them**.

Abstracts oral presentations

Concurrent sessions I

Friday, December 3 from 13.30 - 14.30 hrs

Session A. To be or not to be

WN-C659

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

Marcel Broesterhuizen

Faculty of Theology, Catholic University Leuven (Belgium)

My paper is an ethical and theological reflection on the large difference between hearing and deaf persons as to the ethical evaluation of cochlear implantation of young deaf children and genetical research of deafness. For hearing persons, these are important contributions to deaf people's quality of life, and as such an ethical necessity, whereas most deaf people themselves consider them a threat for quality of life. The aim of my paper is to explore the background of this difference and to propose a way of dealing with this difference in daily contacts between hearing and deaf persons. This exploration takes place through literature study and through the application of theory from the fields of cultural anthropology – especially Devlieger's theory of disability as culture – and theology – especially John Hull's view on disability as a world-generating condition and McFadyen's theological view on personhood – on the findings from literature study. My conclusion is that the hearing and the deaf view on cochlear implantation and genetical research stem from and have their own logic in different cultures, different worlds, and different cosmologies. The difference between these two competing views on deafness and its treatment cannot be resolved by an exchange of arguments with one winning view as a result, but can be dealt only with in continuous dialogue and negotiation.

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

Karen Mogendorff

Wageningen University

Aim

Researchers increasingly employ their own experiential knowledge in social (disability) research to enrich scientific understanding and to ensure that end-users benefit from it. Still, there is little published about how using one's own embodied knowledge in research affects the scientists' quality of life. Based on anthropological research at home - fieldwork but also subsequent publication- I hope to shed some light on and try explain the long term effects of working with experiential knowledge on relations (friendships, professional and public contacts) in order to further our understanding of the consequences of the choices that come with using one's own experiential knowledge as a professional.

Method

Reflection on the effects of anthropological research at home on the researcher's quality of life, in terms of well-being, relationships and ability to empower and disrupt in relation to the existing literature. When appropriate informants' experiences with using embodied knowledge will be included.

Results and conclusions

Use of embodied knowledge empowers and makes vulnerable in several ways. This partly depends on to what extent one uses one's own embodied experience as a research tool. I put, for instance, one of my ways of dealing with negative responses to my impairments on hold in order to better understand the process of social exclusion and stigmatization of disabled people. Writing and publishing invites disclosures or comments of people you know or have known. This all may be very informative but not necessarily pleasant, precisely because it is also personal. Embodied knowledge is on the other hand rewarding: one can put negative, personal experiences to good use and the research process may enable the researcher to develop alternate ways of dealing with disability in his or her everyday life. Finally, both vulnerability and empowerment may be partly produced by the way using embodied knowledge rearranges 'traditional' boundaries between the private, the public and the professional.

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

Jenny Boumans and Marianne A.J. van Bakel
Trimbos-instituut, Section Reintegration, Utrecht

Aim

To give a versatile reflection on the frequently used term 'empowerment' in relation to disease, (psychiatric) vulnerability and disability.

Methods

A combination of theoretic exploration, literature review, and case study (HEE). The presentation will consist of: A) a conceptual framework of empowerment based on (historical) theory, B) (first) results of a literature review on empowering interventions in the context of care and welfare, and C) an explanation of the role of the concept empowerment in the HEE practice.

Results

Empowerment is often used in a shallow way but is in fact a complex multidimensional concept that essentially is about individuals potential to be a subject of their own life. Critical theory can be helpful to understand this deeper meaning. After presenting a short introduction to theoretic approaches of empowerment, the results of a literature review on empowering interventions in both care and welfare, are presented. This study is currently carried out. The results are not yet available at the time of submission of this abstract.

An important example of empowerment practice is the HEE programme. The meaning of empowerment in this context is learning to use your own power/strength to regain control over your life. It is about making your own choices and implementing changes. Both creating awareness and taking action are necessary steps to do this. To enable these empowerment processes, HEE deploys *experiential knowledge*. In the presentation we will reflect on two important pillars of empowerment: peersupport and self-help.

Conclusions

Although the concept of empowerment is often used in a too shallow way, it is in fact a multidimensional and very meaningful concept in the context of studying, understanding, and dealing with disease, (psychiatric) vulnerability and disability.

* HEE is the (Dutch) abbreviation of 'Herstel, Empowerment en Ervaringsdeskundigheid'. The English translation is: Towards Recovery, Empowerment and Experiential knowledge. HEE is developed by long term mental health care users in cooperation with the Trimbos-institute. The programme combines the strategies and methods of user initiatives which are thought to account for their success.

Session B. What distinguishes disability studies?

WN-C669

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

Jeannette Pols

AmC/ University of Amsterdam

The emancipation of people with handicaps and chronic diseases lead to new public positions for those concerned, such as the citizen, the consumer, and, recently, the patient 2.0.

In this paper I will analyse these positions, and specifically, the place of medical knowledge within them. I will argue that disability studies' proud rejection of discourses of biomedicine may paradoxically strengthen these same discourses. This comes at the price of a neglect of the particular kinds of knowledge that people with handicaps or chronic diseases develop and use to live with their handicaps and diseases on a daily basis. As a consequence, this knowledge cannot be shared with others and is only developed locally. Interesting public roles for people with handicaps and chronic diseases run the risk of being ignored. Material from ethnographic studies in the practices of people with severe lung-disease (COPD) will be presented to argue the case.

2. Disability studies and aging

Lieke van Heumen, MSc.

PhD Student in Disability Studies, Institute on Disability & Human Development, University of Illinois at Chicago, USA

Aim

As more persons are living longer with a disability, whether the onset is early in life or comes with aging, there has been a greater intersection of the approaches to disability and gerontology. However, there is a lack of conceptual crossover and integration of scholarship between these two fields (Kennedy & Minkler, 1999; Putnam, 2007). Disabled people who are aging are often overlooked (Zarb, 1993) in research in both fields. The aim of the paper is to contribute to incorporating approaches to aging in disability studies. In examining the two fields it will use social relations and loneliness in older adults with intellectual disabilities as an example.

Method

This paper examines the disability studies literature on aging (e.g. Zarb, 1993; Zarb & Oliver, 1993; Priestley, 2003) as well as the theoretical exchange between the fields of disability studies and gerontology (e.g. Kennedy & Minkler, 1998; Kennedy, 2000; Putnam, 2002). It explores the importance of combining these fields as an interdisciplinary approach in informing both disability and aging discourses.

Results

Research on aging is scarce in disability studies. Disability studies has the tendency to distance itself from associations with aging, due primarily to the centrality of workforce participation in both disability theory and policy. Vice versa gerontology has distanced itself from associations with disability, stressing that covariance is not equivalence. However, there are many similarities between the constructions of disability and old age. Both categories are perceived as dependent and non-adult social categories. Approaches in critical gerontology have important parallels with disability studies. Investigating social relations and loneliness in older adults with intellectual disabilities framed within the intersection of disability studies and gerontology can give more insight into this topic.

Conclusions

In informing disability studies it is essential to incorporate aging theory and the experiences of older people. The development of the field of critical gerontology gives opportunities for bridging disability studies and gerontology. As more people are living longer with disability this becomes increasingly important. Social relations and loneliness in older adults with intellectual disabilities should be studied as an intersectional issue since both disciplines can contribute to this topic significantly.

3. Sharing the loop: A grounded approach to relating to and through medication

Preferred medium of presentation

Joan van Ee

Utrecht University, Gender Studies Dept.

Aim

This preliminary study aims to challenge normalising understandings of sustained medication use, according to which a life with medication should be considered largely in terms of its resemblance to a life without medication. Instead, it seeks to explore people's lived experience of long-term medication use on its own terms.

Methods

Semi-structured, face-to-face interviews were conducted with three men and five women between the ages of 23 and 75, living in the Netherlands, all of whom had been using or had previously used a form of prescription medication for several years. No one form of medication was specifically targeted, and all eight interviewees had used at least one substance for a condition that was particular to them. All interviews were conducted, recorded, transcribed and analysed by the author, who has first-hand experience of sustained medication use herself. The interviews were analysed according to Kathy Charmaz's constructivist take on grounded theory, by seeking out patterns and salient features without forcing them to fit a preconceived interpretive framework.

Results

The data suggest that long-term medication use is a social-relational practice that extends far beyond the obvious doctor-patient dynamic. Any number of individuals connected to a medication user may be involved in what is itself a complex relationship: the negotiation of meaning through which users makes sense of, and respond to, a given substance's (side) effects. The process resembles a feedback mechanism, both literally and in the colloquial sense of being kept in or left out of 'the loop'. Work is a recurrent factor in interviewees' understanding of their medication use, yet those they involve in their loops tend to be family members rather than colleagues.

Conclusions

Though limited in scope, this brief study suggests a number of areas for further research. A conceptual shift seems warranted, a recasting of medication use as social action rather than an individual choice between compliance with and defiance of a regimen. Where the latter reduces a prospective user's scope of action to what has been prescribed to them, medication loops highlight a wide range of opportunities for conscious intervention.

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

Auditorium

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

Wanda Katja Liebermann

Harvard University, United Kingdom

This paper revisits the 1962 watershed cultural event, “Open Het Dorp,” Holland’s famous televised fundraiser to construct a community for the physically disabled, and the subsequent village design. I examine the role that the architecture and architectural representation played in the enactment of different Dutch citizenships, including the residents of Het Dorp, through its design and related spatial practices. I make two main arguments: first, that the collective action of “Open Het Dorp”, the “good cause” of accommodating the disabled, was a critical step in nation-building, and secondly, that public ambivalence about the personhood and citizenship of its projected residents was embodied in the architecture through a design that collapsed a utopian vision within an institutional framework. The resultant design strategy of the “street” reproduced this paradox, both enacting and denying the autonomous citizenship of the residents. Drawing on scholarship from science and technology studies (STS), especially ANT (actor-networktheory) I attempt to show that Het Dorp, as a sociotechnical artifact, was both the product of human agency and structured social action. This approach analyzes design in the wider anthropological and historical cultural-political context by combining representational material, mostly the “Open Het Dorp” series of television programs, interviews with users and designers, and detailed descriptions of the material environment.

2. Does disability affect quality of life?

Silke C. Hoppe

Universiteit van Amsterdam

Aim

It is often thought that disability negatively affects a person’s quality of life. People assume that the worse the functional disability the more problems people experience with their situation and the lower their quality of life is. In this presentation I want to demonstrate that having a chronic and disabling illness does not necessarily affect quality of life in a negative way, but can even affect it in a positive way. Furthermore I want to stimulate the discussion about which factors shape people’s perception of quality of life.

Methods

The research on which I base my presentation took place in Dublin among 22 people diagnosed with Multiple Sclerosis. I used qualitative research methods, mainly interviews, to gather my information. In my current research I analyse how people with MS in Amsterdam experience their illness.

Results

People experience their illness in many different ways. Some have normalized their illness and integrated it into their daily lives; others experience many problems with their disability. But I also met people who stated that getting MS gave their life a positive turn. The question that rises is how it can be explained that some people struggle with their illness, while others are dealing well with it. I argue that it is not possible to find one or two factors like social support, employment, gender, age, or functional disability which explain for those differences in quality of life and illness experience.

Conclusions/Discussion

More research is needed in order to find out what is important in determining people’s illness experience and perception of quality of life. In my current research I focus on the aspect of reciprocity as an underlying factor. In my presentation I would like to discuss with the audience which factors predominantly shape the illness experience and perception of quality of life and how people’s perceived quality of life could be improved.

3. Quality of life: measure or listen

Dick L. Willems

Academic Medical Center / University of Amsterdam

Aim

The question of this theme, “how does disability experience affect quality of life”, can only be answered if we know how to study quality of life. The aim of this paper is to argue that disability studies should not adopt a quantitative interpretation of QoL as it is used in medicine. I will do so by discussing qualitative ways of studying QoL. The concept is often used quantitatively, within Evidence Based Practice, as part of outcome measurements in medical trials, using generic scales like the SF36 or disease-specific scales such as the Minnesota scale for chronic heart failure. Some more sophisticated quantitative scales such as the SeiQoL allow patients to indicate the domain of life that they want the QoL measurement to be about. All of this conveys the slightly paradoxical idea that quality of life is quantifiable, that it may be and must be expressed in numbers. Increasingly however, there are doubts as to the extent to which the numbers on QoL measurements reflect the lived quality of life of a person.

Methods

Results from two studies performing think-aloud protocols and one qualitative interview study will be presented.

Results

Two studies, one performed in people who were severely disabled due to heart failure, and another in people with cancer. have shown, using so-called think aloud methods, a large discrepancy between what people tick on a QoL questionnaire and what they say if they are asked to think aloud while ticking the boxes. For instance, when asked whether they were still able to work in their garden (scale 1-5), many interviewees who said they had no garden either ticked 1 (“I don’t have a garden, so how could I work in it”) or 5 (“I could work in a garden if I had one). Still others ticked 1 saying they had always detested working in gardens.

Conclusion

The conclusion from these and other studies is that the question: “how does disability experience affect quality of life” should be investigated primarily with qualitative methods – more listening than measuring. I will end the paper by a description of a qualitative study in persons with advanced COPD that did just this.

Session D. Multi Cultural Perspectives on Quality of Life

WN-F607

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

Jos Philips Ph.D.

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

Aim and content

Doing justice to diversity in quality of life as disabled people experience it seems quite obviously at odds with approaches to their quality of life which are in some sense 'standardized', e.g. quite general, almost exclusively objective, or even explicitly simplified. Standardized approaches may be of many sorts and intended for many purposes – one may, for example, think of declarations of human rights, lists of capabilities, or of certain measurements of quality of life. In this paper I intend to investigate to what extent such approaches may be, contrary to first appearances, not inimical to acknowledging the diversity in quality of life as experienced by disabled people, but rather compatible with it or even, in certain policy contexts, needed to recognize such diversity.

The reason for investigating this is that there seems to be a dilemma here: many relatively crude approaches of quality of life and related issues do seem to have difficulties in recognizing the diversity of quality of life as experienced by disabled people, yet it seems that without some of these rather crude approaches we would lose quite a lot in certain important practical contexts – as I will try to make clear by examining the recent UN Convention on the Rights of Persons with Disabilities, Martha Nussbaum's list of capabilities (real freedoms), which is primarily meant as a political account of basic justice, and the human development index (which only looks at life expectancy, education, and income) as well as some related measurements.

Method and possible results

The paper's method is to carefully lay out the arguments on the different sides of the mentioned dilemma (in a number of varieties of this dilemma). As a result, it will become clear whether the thesis can be vindicated that rather crude approaches to quality of life are in the end in many contexts quite compatible with, and even needed for, recognizing many diversities in quality of life among disabled persons.

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

Walton O. Schalick, III, MD, PhD

Director, Disability Studies Cluster; Departments of History and of Pediatrics, University of Wisconsin, Madison, WI, USA

Aim

To understand the competing bureaucratic meanings of “quality of life” with respect to children with disabilities in France, Germany, the UK and the US from 1802 to 1970. First created in the late 1960s by American operations researchers, economists and psychologists, measures of healthcare related quality of life (QALYs) came about largely because of the entrance of the US federal government into financing healthcare via Medicare and Medicaid. Similarly, in the UK, standardization of healthcare technologies arose in the late 1960s with revisions in the National Health Service. These measures spread in European countries variously from the 1970s to the 1990s. QALYs bled down into disability more specifically in 1993 when the WHO queried the ‘burden’ of international disease and disability, so generating the DALYs. Thus a contemporary focus upon disability and quality of life has come in large measure from a bureaucratic need for utility functions to allow governments and like agents to ‘justify’ distribution or withholding of resources.

Methods

Using a large collection of archival sources from France, Germany, the UK and the US and historical methodology, this paper describes case examples of the bureaucratic assessment of life quality and ‘quality healthcare’ service for children with disabilities in France, Germany, the UK and the US from 1802 through the 1960s.

Results

As objects not just of a “medical gaze,” but also a bureaucratic gaze, the quality of life of children with disabilities slowly came into focus in a modern sense. But, paradoxically, the more philosophical *lebenswertes leben* focus long antedated the corporate quality movement of the 1960s, offering a subtext to the contemporary debates about QALYs and DALYs.

Conclusion

The resulting disability narrative runs counter to the argument for quality control based efforts in the biomedical platform model of Keating & Cambrosio (2003).

Rather it echoes the tension between capabilities driven contractarianism and modern consequentialism in political philosophical arguments within governmental bureaucracies that anatomize the disabled child’s body.

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

Joachim Gerich

Department of Sociology, Johannes Kepler University Linz, Austria

Aim of the study

The aim of the presentation is to answer questions about the role of social networks for quality of life in a deaf population. On the one hand this refers to the question whether a specific network composition (with respect to deaf and hearing network persons) provides positive resources for quality of life. On the other hand, the paper is aimed to identify pathways of moderator and mediator effects (including self-efficacy and communicative skills) between social networks and quality of life to provide deeper insight into the possible mechanisms of network influences.

Methods

A dataset of a survey with 107 elder members of the deaf community aged between 45 and 81 years (M=61 years) is used. Interviews were conducted with self-administered computer-based video-questionnaires. Network size was measured with respect to three different types of social relationships (intimacy, support and companionability) separated for deaf and hearing network partners. Quality of life was measured with the WHO-QOL domain of global quality of life. Self-efficacy was measured with a German version of the Generalized Self-Efficacy scale. Communicative skills were measured with three questions regarding the self-rated competence to communicate in sign-language, text comprehension and the ability to understand the communication of hearing persons.

Results

It was found that a larger social network is significantly associated with higher quality of life. This however, is mainly attributable to the size of the deaf network. Although the hearing networks size is also associated with a higher quality of life, this is due to the correlation of deaf and hearing network size (i.e. persons with larger deaf networks also tend to maintain larger hearing networks). The hypothesis of a particular positive effect of a bicultural network composition on quality of life however, has to be rejected. Bicultural networks do not affect quality of life in a way that goes beyond the main effect of deaf network size. It was found that the effect of deaf network size on quality of life is mediated by personal resources regarding self-efficacy and communicative skills. Further on, evidence was found for the functional equivalence of social and personal resources. It was shown that negative effects of reduced personal resources (a lack of communicative skills or reduced self-efficacy) on quality of life could be compensated by a larger deaf network (and vice versa).

Conclusions

The results suggest - at least for elder deaf persons – that deaf networks are an important source for quality of life. Social capital in the sense of deaf relationships is the source for personal resources that contribute to life quality. Of course, still other resources (like education, professional occupation, parental coping in childhood and other factors) may influence the development of personal resources. However, especially for those with such initial conditions that do not support the development of high personal resources, deaf networks are a compensating source for life quality.

Concurrent sessions II

Friday, December 3 from 14.45 - 15.45 hrs

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

Auditorium

1. Existential wellbeing and quality of life

Dorien Veltens and Axel Liégeois

Faculty of Theology, Catholic University of Leuven, Belgium

Aim

The aim of this paper is to argue for the importance of existential wellbeing of persons with an intellectual disability as one dimension in the theory of quality of life.

Method

The paper is based on the study of literature on philosophical and theological anthropology and on quality of life persons with intellectual disability, enriched by personal experience in living with persons with intellectual disability.

Results

In the literature on philosophical and theological anthropology, a prominent approach is a holistic and multidimensional view of the human person. In this view, there are several essential and complementary dimensions of the human person and the existential or spiritual wellbeing is considered as being one of them (Janssens; Sulmasy; van Deurzen; WHOQOL). In the literature on quality of life and intellectual disability, on the other hand, nearly no attention is paid to existential or spiritual wellbeing as an essential dimension of quality of life (Schallock; Petry, Maes and Vlaskamp). To acknowledge this dimension, however, a necessary step is the recognition of the holistic and multidimensional character of human life and of quality of life in general, and especially for persons with intellectual disability. People draw on spirituality and faith to discover the meaning in their daily life, they use it as a way of coping with moments of joy and pain, for prevention and recovery of illness.

Conclusion

An appropriate support to enhance the quality of life of persons with intellectual disability includes an adequate existential accompaniment of these persons. Therefore, we started a research project that aims to develop a theological framework grounding existential accompaniment for persons with intellectual disability. The research uses two sources of knowledge and methodologies: first, a qualitative empirical research to explore the current practices of existential accompaniment, and second, a theological study of literature towards a view on existential accompaniment for persons with intellectual disability. A theologically open and adequate framework will be designed and afterwards validated by means of a Delphi research and an Expert seminar.

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

Julia Bahner

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

Aim

The aim of this study was to analyze the living conditions of physically disabled people from the viewpoint of sexuality issues with regards to personal assistance services, identity and attitudes in society on disability and sexuality.

Methods

Interviews were conducted with ten physically disabled people, a personal assistant and a physically disabled person working with a project on disability, sexuality and personal assistance issues in the Federation of Young Disabled. In addition, Internet observations were conducted in the forum of www.funktionshinder.se (Swedish disability site). The data has been analyzed using grounded theory.

Findings

Not much research is done on sexuality issues for physically disabled people. Even though we live in a society where sexuality takes up a lot of space in the media, the culture and is acknowledged to be of great importance for every person's wellbeing, the sexuality of disabled people is often not recognized and discussed. We have little knowledge of how these attitudes influence physically disabled people and their forming of a desired identity and sexuality.

Disability and sexuality is explained in terms of being socially constructed. Using the social model of disability and the theory of sexual scripting (Simon & Gagnon 1984), the results show that disabled people's sexuality can be surrounded by barriers of societal and professional taboos and judgmental attitudes. This makes the experience of identity, personal assistance and sexuality ambivalent for the individual.

Conclusions

Forming a desired sexuality and identity can be harder for physically disabled people in terms of fighting against judgmental attitudes about both disability, personal assistance and sexuality, when struggling for recognition as a sexual being and forming a sexuality which includes the desired components of assistance or otherwise.

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

Cretien van Campen¹, Marc van Santvoort²

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

² Bureau Onderzoek en Analyse, Amersfoort, The Netherlands

Aim

People with chronic disabilities report the lowest subjective well-being (SWB) in many countries. In some countries the differences in SWB between people with and without disabilities are smaller than in other countries. Data of the European Social Survey were analyzed to: 1) describe the inequity in SWB in 21 European countries, and 2) search for the main factors of this inequity in SWB.

Methods

40,600 persons, including 2,436 persons with severe chronic disabilities were surveyed on a range of topics. SWB was measured with multi-item scales for 'satisfying life' and 'emotional well-being'. Variables on disability, socio-demographics (age, gender, household composition, education, income), participation (paid and voluntary work, social contacts), and personal competences (optimism & self-esteem, resilience, autonomy, accomplishment, capacity, engagement, meaning & purpose, supportive relationships, trust & belonging, vitality) were entered stepwise in regression models.

Results

The descriptive results showed that the differences in SWB between persons with and without chronic disabilities were smaller in North-European countries than in East-European countries. Competences were the main factor in explaining differences in SWB, in particular the factors 'self-esteem and optimism', 'vitality', and 'supportive relationships'. This suggests that programs for empowerment, social cohesion, healthy exercising are expected to have the largest impact in diminishing the inequity in SWB between people with and without disabilities.

Conclusions

We conclude, first, that inequity in subjective well-being is explained most by personal competences, and less by socio-economic status and participation in most countries. Second, optimism & self-esteem, social supportiveness and vitality have the largest positive impact on increasing levels of SWB of people with disabilities.

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

WN-C659

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

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

Kenniscentrum UWV

Aim

The policy goal of current social security schemes is to enhance participation in work for all disabled or chronically ill persons in an inclusive labour market. UWV aims to maximize employment of its clients. The aim of our study is to evaluate the outcomes of this policy. Therefore we are monitoring the work status and trends in the work status of all recipients of disability benefits and all applicants who failed to qualify for disability benefits in The Netherlands.

Methods

We used administrative data to assess work status of several cohorts of applicants of disability benefits who were assessed to be able to work although having a medical condition. Cohorts are followed during three years: 2007, 2008, 2009. Work status was assessed on a specific date in each year of follow-up. There is no response bias or loss to follow up, since we have almost complete information available in the data systems of UWV: records of all employees and all applicants of benefits were available over these years. We lack information about work status of self employment: the only missing link in the data.

Results

Between 2007 and 2008 the percentage of working partially incapacitated persons rose, but dropped again in 2009. Probable cause of the drop is the economic crisis. If we concentrate on new applicants, we see about half of them is working. The majority of the working persons (60-80% in three subgroups) works in a regular job, and a minority in a temporary job (3-8%). For about 3-5% of all cases UWV provided the client with a provision to work. For 29-35% of all these clients UWV provided rehabilitation services. A special group are partially incapacitated applicants who did not have a regular employer during onset of the disability or illness that led to application for a disability benefit. These are employees who were on unemployment benefits, or who were so-called flex-workers. Their return to work rate is significantly lower compared to partially incapacitated employees who had a steady employment relation.

Conclusions

The drop in the percentage of working clients in 2009 is higher compared to the drop in total employment. This suggests that the economic crisis hit harder on participation in work of partially incapacitated persons than of the rest of the work force.

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

Annette Hendriks, Karen Schipper, Linda Dauwerse, Veronique Willems and Tineke Abma.

VUMC, EMGO+ institute for health and care research, Dept Medical Humanities, Amsterdam
programma Autonomie en Participatie in chronische zorg

Aim

The aim of this presentation is to show that social and societal participation for people with an Acquired Brain Injury (ABI) depends partly on their personal power to recover and adjust to society, and partly on the facilitating and constraining factors of our contemporary society.

Methods

In the study we examined the disabilities and the specific needs of persons with Acquired Brain Injury (ABI) concerning their societal and social participation. We used a qualitative, participatory research approach to find out the patient perspectives on participation. This perspective was central in each step of the definite action plan. Through depth-interviews (n=26) and focus groups (6 groups, 36 participants) we collected and analyzed issues concerning participation. The research team was composed of academic researchers and those who have experiences with ABI as a (former) patient or relative to live up to what the study was aiming for; more equality and participation of those with a disability.

Results

The findings demonstrate that both personal and environmental factors and their interaction influence how and to what extent people with ABI experienced their disabilities. The disability derives its meaning from the environment, but how to deal with it in the environment, depends also on personal characteristics. In this presentation we focus on the developments within society in the areas of knowledge and policy, technology and digitalism, which have an influence on participation, and how persons with ABI handle these. Also, characteristics of society itself, like individualism, bureaucracy, quickness, performance-orientation and a bombardment of incentives may hinder participation. Yet, people with ABI were able to survive and hold on to their identity and future wishes. They show resilience and develop individual power to find a meaningful way of live in our complex society.

Conclusions

A disability studies' perspective on people with ABI means an eye for the environment/society combined with the psychological perspective of resilience. Participation of people with ABI in our contemporary society requires the power for being oneself and contributing meaningfully to our society as well as an enabling environment that creates space for people with ABI.

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

Rick Kwekkeboom PhD, MSc

Professor Community Care, Amsterdam University of Applied Sciences

Aim

The research was carried out among people with learning disabilities or chronic psychiatric problems, living independently in the south-west region of the Netherlands. Aims, among others, were to provide insight into the way these people participate in society and into possible correlation between participation and characteristics of those concerned. Furthermore the study explored whether and to what extent participation contributed to giving people with this kind of disabilities a feeling of satisfaction and happiness.

Methods

The research was conducted by interviewing 400 respondents, using a standardised questionnaire, concerning the various life domains as health and disabilities, housing situation, support, employment and social network. A model was developed for the analysis of the relationships between forms and conditions of participations as well as the relationship between participation and happiness. The model kept open the possibility that satisfaction of life or happiness is not determined only by the form of degree of participation, but also depends on other factors.

Results

The main outcome of the calculations is that participation in society is not the most important condition for happiness of people with this kind of disabilities. In addition to their own attitude to life, it is their satisfaction with a number of domains of life treated in the model as determinants of participation which determines respondents' happiness. This is in line with the ranking of life domains: for the respondents health, housing situation and help from their social network are the most important. A positive attitude to life is not only found to make the most important contribution to satisfaction with life and happiness, it also has the biggest influence on participation.

Conclusions

A conclusion that can be derived from these results is that there are only limited possibilities for promoting the participation of people with these disabilities or chronic psychiatric problems. Furthermore the outcomes suggest that increasing their participation will not necessarily contribute to their happiness. This underlines the importance of 'empowerment', which is primarily concerned with this concept.

Session D. Multi Cultural Perspectives on Quality of Life.

WN-C669

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

Frank A. Renders

KULeuven, Fac. of Social Sciences, Anthropology, Belgium

Aim

Implementation of the concept 'intellectual disability' in the study of western and other cultures results in an erasure of cultural differences. This paper discusses the difference between cultural differences

Method

Two various contexts are portrayed: (1) Different tracks are established that promote a better quality of life in a residential institution for people with intellectual disabilities: a) creation of a physical environment that structurally pushes the ontological reality of the disability experience into the background. b) Creation of a collective social body (e.g. team of care-givers) that installs an unambiguous mental horizon in the disabled body. These tracks guarantee the safety and protection of the residents. (2) Implementation of the concept 'intellectual disability' in cross-cultural research results in an erasure of cultural differences. Cultural differences are distinguishable by their culture-specific configurations of learning. 'Theoretical knowledge' is dominant in the West, and is characterized by a 'knowing-about'. It incites the portrayal of an orderly perspective of the world and its phenomena.

Results

Cultural differences are erased differently. (1) Emphasis in residential institutions is on creating optimal conditions to nurture the mental and physical health of the disabled body. As a consequence, the ontological reality of the disability experience is transformed into a symptom of their disability. At the same time, insufficient space is available to reflect on the ontological reality of the experience of the caregiver. (2) Western knowledge is reproduced in non-western societies by means of the concept 'intellectual disability'. It results in a horizontal approach of cultural differences, and is described by the notion 'descriptive acquaintance'.

Conclusion

Quality of life and intellectual disability both embody theoretical knowledge. This knowledge transforms 'othernesses' into variants of a single model, namely the basic structure of the West itself. A cultural model of intellectual disability is constructed that takes the difference between cultural differences as its starting point.

2. Quality of life in Thai perspective

Silatham Sermrittirong, Raj Pracha Samasai Institute,

Department of Disease Control, Ministry of Public Health, Thailand

Thailand is a middle income country situated in Southeast Asia. The population is around 66 million with 10-15% living under the poverty line. Quality of life is defined as reasonable standard of living. In order to evaluate the quality of life of Thai people, 42 indicators based on Basic Minimum Needs were defined.

These indicators are grouped in 6 categories. They are; health, housing, education, income, Thai values and participation in community activities. Local organizations are obligated to conduct a survey every year to identify which indicators are not achieved their minimum target values by each household. This evaluation was used as basic information for formulating a local plan of action.

It has been found that in the year 2008, at national level, 20 indicators were achieved while 22 indicators were not. Most of achieved indicators belong to health and education aspects. It is interesting to note that among indicators not achieved are those that measure the performance of household members in taking care of the elderly and people with disability.

Regarding the quality of life of people with disability such as people with leprosy, a study was conducted to identify the quality of life of people with leprosy related disability who received monthly allowance from the government. It measured 4 aspects of life; physical health, mental health, social relationship and environment. It was found that 56.4% has moderate level, 40.4% has good level and only 3.2 percent has low level of quality of life. This level of quality of life is determined by the study which had been done in general population.

Conclusion

Apart from taking the Basic Minimum Needs into consideration, quality of life in Thai perspective also consider Thai values as one of six important components to be measured. However; some of Thai values indicators are not achieved their minimum targets. This may be because the target values are set as high as 100%. Regarding the quality of life of people with leprosy related disability, there was an attempt to measure their quality of life. It was found that only few of them has low quality of life. This may be because the subjects of this study were the patients who had received monthly allowance from the government who had been secured in terms of economy.

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

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

*VU University, Faculty of Earth and Life Science, Amsterdam, Netherlands.

**NLR (Netherlands Leprosy Relief), Biratnagar, Nepal

***Enablement, Alphen a/d Rijn, Netherlands

****B.P. Koirala Institute of Health Science, Department of Community Medicine, Ghopa, Dharan, Nepal

Background: In Nepal many people live with leprosy-related disabilities. The objective of this study was to evaluate differences in socio-economic characteristics, quality of life (QOL), perceived stigma, activity and participation differences among people affected by leprosy as a group and between this group and the general population, and to identify prime determinants of QOL among the leprosy-affected people.

Methods: People with leprosy-related disabilities (N=100; 54DGI/46DGII) and community controls (N=100) were selected from Morang district, South-East Nepal, using quota sampling. QOL, perceived stigma and participation and activity limitations were measured using the Nepali abbreviated version of the World Health Organization Quality of Life (WHOQOL) assessment and the Nepali versions of the Jacoby Scale, Participation Scale and Green Pastures Activity Scale (GPAS), respectively.

Results: Total QOL, participation and activity levels of people affected by leprosy were worse than those of the general population. Regression analysis showed that the ability to maintain a family, satisfaction with health, training, sex, activity and participation limitations (the latter for QOL only), perceived stigma and living situation (i.e. joint family, type of house) were significantly associated with a deterioration in QOL and higher participation restriction in one or both of the grading groups.

Conclusion: There is an urgent need for interventions focused on quick referral of people with leprosy to minimize the development of visible impairments, creating more public awareness, providing (financial) support for income generating projects and or vocational training to leprosy affected people and encouraging them to be involved in all community development activities. The current results indicate that such measures would help improve the quality of life of people with leprosy-related disabilities.

Concurrent session III

Friday, December 3 from 16.15 - 17.15 hrs

Session A. To be or not to be

WN-C659

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

Lineke van Hal, Agnes Meershoek, Angelique de Rijk, Frans Nijhuis
Maastricht University (The Netherlands), Faculty of Health, Medicine and Life Sciences
Research school CAPHRI, Department of Health, Ethics and Society

Aim

In Western welfare states, labour participation is increasingly considered a vital aspect of taking part in society. To support people with a work disability in the process of returning-to-work, vocational rehabilitation programs are called into being. In these programs, much attention is paid to the skills that clients should develop in order to return-to-work. We argue, however, that vocational rehabilitation is more than the acquirement of skills. We aim at showing that further attention should be paid to clients' processes of identity work during vocational rehabilitation programs, in order to create more inclusive vocational rehabilitation support.

Methods

Qualitative data were gathered by life story interviews. The study, that took place in the Netherlands, had a longitudinal design; three semi-structured interviews (3 quarters - 2 hours) were conducted with an interval of six months. Participants ($45 \geq n \geq 35$) were selected by purposive sampling. Inclusion criteria were: received a disability benefit over five years; underwent a re-assessment of disability; started with a vocational rehabilitation program in 2006 or 2007. Analyses were based on principles of grounded theory and typologies of (illness) narratives.

Results

The various ways people speak about their body, self and society and their relation towards past, present and future, reflect their *identity work* (i.e. the dynamic and contextualised process of identity construction). These processes of identity work constitute different narratives regarding return-to-work. Based on the performed identity work of people with a work disability, an analytical division is made between 'separative', 'integrative', and 'pending' narratives. The performed identity work in these narratives is linked with the way in which the narrators relate themselves to return-to-work. Therefore, processes of identity work could be an important starting point for refining vocational rehabilitation support.

Conclusions

The presented typology can make vocational rehabilitation professionals more sensitive to processes of identity work of people with a work disability, and therefore support more inclusive vocational rehabilitation. Based on our results, we recommend further exploration regarding the different ways in which processes of identity work could be used in practice and its possible consequences.

2. Being an entrepreneur, having an impairment.

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

PhD-student at the Urban and Regional Studies Institute, Faculty of Spatial Sciences, University of Groningen, the Netherlands.

Aim

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

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

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

Method

For this paper, we conducted 33 in-depth interviews with self-employed people with disabilities. These interviews were transcribed, coded and analysed through the content analysis programme MaxQDA.

Results

The respondents indicated that they certainly have a 'disability identity'. It is part of who they are and over time it has helped shape their other identities. However, almost all respondents say that their disabilities are only a matter of secondary importance. More important for them are their distinct entrepreneurial identities. Even though some respondents state that their disability has shaped their entrepreneurial self, the relationship also exists the other way around. By being an entrepreneur, you can prove yourself as also existing outside or without the disability, as being more than just somebody who is disabled. That is why they also think it important to present themselves as entrepreneurs, and not as someone with a disability.

Conclusions

Whereas the respondents are entrepreneurs, they merely have impairments. Most of the respondents are 'Entrepreneurs with disabilities', and not 'Disabled Entrepreneurs'.

3. "Definitions of Disability and its implications"

Dr. Brigitte A.G. van Lierop

Kennis & Innovatiecentrum CrossOver, Nieuwegein, The Netherlands

Many definitions exist around disability. Much is unknown about the impact of the different definitions on data gathering, research and policy development concerning the participation of persons with a disability. This presentation focuses on the different definitions and its possible implications on the participation of persons with a disability and therewith on the impact of the use of definitions on data gathering, research and policy development. It also touches the possibility of organising research around the use of different definitions and its impact on knowledge development around participation of persons with a disability.

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

Auditorium

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

Hermans, C.

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

Today it is a more and more accepted thesis that human beings learn and experience through bodily movement. Deleuze states: "Rather it is a question of making movement itself a work, without interposition;...of inventing vibrations, rotations, whirlings, gravitations, dances or leaps which directly touch the mind" (p.9, 1968).

Since it is precisely through the body that we have access to the world, bodily and sensorial processes play an important role in the construction of a sense of self. In this PhD research I will argue that kinaesthetic empathy plays a crucial role in the interplay between self and other and therefore is a useful tool in art projects for children with special needs.

In the presentation I will argue why dance education for children is fruitful in understanding and developing a sense of self. I will focus on kinaesthetic empathy and mirroring techniques as ways to stimulate the notion of intersubjectivity, embodied agency and the understanding of other 'minds'. Specifically I will focus on children with special needs: 1) children with autism, 2) children with a prelingual hearing loss and 3) children with a conduct disorder. Research finding will be used to explain how these dance projects can stimulate another way of thinking, namely a bodily way of thinking.

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

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

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

Aims

This presentation will summarize research related to the assessment of quality of life and the efforts undertaken at the Centre for the Arts in Human Development (CAHD), to evaluate the construct as it applies to individuals with Intellectual and Developmental Disabilities (ID/DD). The current understanding of the construct and the challenges in assessment and measurement in the lives of individuals with ID-DD will be reviewed. One of the best indicators for quality of life is the opportunity for empowerment and choice. According to Lustig and Crowder (2000) and DeStefano (1991), quality of life is the ultimate outcome measure for rehabilitation and mental health programs.

Methods

The participants' were all adults with ID-DD who demonstrated deficits in communication, cognition, and social skills. Participants took part in each of the four Creative Arts Therapies offered at the CAHD: Art, Music, Dance and Movement, and Drama. An interview was used to assess participants' quality of life over a three-year period to determine whether and to what extent participating in a therapeutic intervention had an effect on their overall quality of life. The interview questions were adapted from Sinnott-Oswald *et al.*'s (1991) Quality of Life Questionnaire, as well as Schalock and Keith's (1993) Quality of Life Questionnaire. The interview questions were selected and adapted with the intent to better understand participants' feelings toward their self-concept, decision-making ability, level of independence and self-control, support systems, general well-being and reasons for participation.

Results

Both qualitative and quantitative data were generated supporting that participating in a creative arts therapeutic intervention can have desirable outcomes and benefits for people with ID/DD. Specifically, as seen in the program at the CAHD, participants seemed to develop and strengthen important personal skills such as self-esteem, confidence, assertiveness, and expressiveness. Of equal importance, participants' overall skills and attributes found to be predictors of quality of life, were positively enhanced; such as choice-making, independence, autonomy, and self-determination.

Conclusions

Participants appeared to have a richer and more meaningful quality of life and overall positive life satisfaction- in all key areas related to quality of life: physical, emotional, intellectual, social, and spiritual.

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

The project is called "Ohrenblicke", it is organized by the association "Blinde und Kunst" (Blind People and Arts) together with "Miramedia" in Utrecht, "Radio Z" in Nuremberg and as leading partner "Radiofabrik" in Salzburg. It is funded by the culture programme of the European union and several other funds. Siegfried Saerberg is a blind participant and conducts the study.

Quality of life includes not only wealth and employment, the built environment, physical and mental health, and education, but also leisure time, and cultural participation. Recent work on subjective well-being has already shown the importance of participation and leisure activities as subjective indicators for the quality of life. They are important to achieve one's personal goals, hopes, and aspirations.

For a long time, listening to the radio has been a favourite recreational activity of blind people. But a full participation in the process of "making radio" demands the opportunity to make radio independently. Consequently, the first aim of "Ohrenblicke" is to enable the blind participants to produce radio shows on their own:

How to conduct an interview.

How to write a feature.

How to edit a radio-programme on the computer.

More than that, the content of the radio shows deals with themes reflecting the differences of the special blind perspective on culture .

In a second step an evaluation of this new experience will be made by "Miramedia" in Utrecht and by a study conducted by sociologist Siegfried Saerberg who works together with the International Research Unit Disability at the University of Cologne.

Methods: The design of our research programme includes interviews of the participants and auto-ethnographic research, for Siegfried Saerberg is also a blind participant in the project.

Although the project is only halfway finished, first conclusions can be drawn:

1. Emotional well-being is important.

2. Nevertheless, life evaluation is not only connected to emotional factors but to a high degree to meaningful experience. E.g., how can I articulate my own perspective in my leisure activities? In this context, negative emotional experiences like stress can be overcome.

3. Live ability of a city increases when diverse venues like radio stations exist where meaningful experiences can be made.

The concept of quality of life can be used in a disability studies perspective to further gain insight into important aspects of enjoyable self-determination and cultural participation. Persons with disabilities define quality of life in the way they enjoy, appropriate and communicate their own life-story and life-style as meaningful experience.

Session D: Multi Cultural Perspectives on Quality of Life

WN-C669

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

Mimi M.Lusli

PhD student at VU University/ Director of Mimi Institute

As a democratic country, embracing diversity is a main characteristic of society in Indonesia. In this context, it is clear that Disability should be embraced as part of diversity. So how about the quality of life of PwD in Indonesia?

In year 1997 Indonesia published a Law concerning on PwD. The Law protects their rights in terms of health and social rehabilitation, education, accessibility and employment. Regarding employment, the Government has applied a 1% quota system of job opportunities for PwD. In education, the Government has applied inclusive education which is open to all students including students with disabilities. In terms of accessibility, the Government has published the technical guideline for accessible infrastructure and building. Also in 2007, Indonesia became one of the signatory of the Convention of the Rights of PwD. By this, Indonesia has the main responsibility to ensure PwD to enjoy their human rights.

Those policies clearly support PwD to have a better quality of life. However, in daily life, these policies have not implemented well due to false perception, unsupportive culture and unsupportive policy undertaking. Consequently, PwD face physical, attitudinal and societal barriers. As a result, PwD cannot fully participate to enjoy their human rights in all aspect of life.

Participation and enjoyment of human rights are important contributors to the quality of life of PwD. The main challenge that they may face is the interaction between themselves and their environment. Therefore the reason for disability is always complex, and can only be understood and addressed in the context of democratic processes by including PwD as part of Indonesian diversity.

A better quality of life of PwD depends on a better understanding and sensitization of PwD by the government and society. To achieve this, mainstreaming disability is an effective strategy to promote PwD as part of human diversity in the democratic process in Indonesia. Through campaigns, training and other social marketing communication, PwD can be helped to have a better quality of life. In this strategy, PwD should be the main actors.

2. “Quality of Life of Persons with Disabilities in Ghana”

Angela Dede Williams

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

Bregt G. Lameris (Ph.D)

University of Amsterdam (Media Studies)

This presentation raises questions about how the representation of madness in psychiatric photographs was related to the definition and perception of madness in the nineteenth century. The aim is to better understand the interrelationship between photographic representations of mentally disordered people and the construction of their cultural identity.

My hypothesis is that the photographs and the way they were used and presented turned portraits of people who were (supposedly) ill, into metaphors of various disorders. This implied that the identity of the portrayed was reduced to the nature of their disease.

In the nineteenth century optical technologies like photography were believed to be more objective than the human eye. As a consequence, in 1848 psychiatrist Hugh W. Diamond started to use photography as a scientific tool to investigate the physiognomy of mental disorders. These photographs – mostly portraits of patients – enabled psychiatrists to compare different stages of diseases, as well as study the diseases and the way they appeared on the faces represented. These photographs were also used to illustrate scientific lectures, articles and handbooks of psychiatry.

The portraits of patients were kept in collections and series. As items of these collections, they were numbered, labelled and categorised according to the various disorders and symptoms the patients suffered from. Summarising, these portraits of individuals functioned as metaphors - as 'pars pro toto' - for specific diseases or disorders. To my opinion the meaning given to the portraits of these people strongly influenced the construction of their cultural identity.

During this presentation these identity-shaping processes will be investigated in order to clarify the interrelationship between psychiatric photographs and the definition and perception of madness in the nineteenth century. Several series of psychiatric photographs from the nineteenth century will be analysed, as well as the photographic images themselves. The framing of these images in series and collections will be taken into consideration, and the way they were categorised, accompanied by texts, and presented in lectures and books will be studied.

Concurrent session IV

Saturday, December 4 from 11.00 - 12.00 hrs

Session A. To be or not to be

BV-0H19

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

Frans Nijhuis, Fred Zijlstra, Henny Mulders
Universiteit Maastricht and UWV-WERKbedrijf

Today's social security systems in all OECD-countries are primarily aimed at promoting participation of people with disabilities in regular work organizations. A variety of supportive measures is available to people with disabilities to enhance their labour market position, as compensation for their obvious disadvantages in competing with other job seekers. As yet, considerable financial and professional efforts did not result in substantial increase of work participation of people with disabilities. It seems that more is needed to establish a more inclusive labour market.

People with disabilities are often capable to perform productive activities, given the proper conditions. Unfortunately in general these conditions are not yet met in regular work organizations. Traditional methods of recruitment and selection as well are aimed at fitting people to the existing standard jobs and standard working conditions.

In the near future this one sided approach of 'matching' a person's capabilities to 'fixed' work demands of organizations will be no longer sufficient to fulfill the need of personal. Due to changes in demography people with disabilities will be needed as well to compensate for labour market shortages. Therefore work organizations will have to develop an alternative approach: fitting the job to the person. Work redesign is necessary to offer jobs and working conditions that fit the individual characteristics of people with disabilities. Experts of the University Maastricht and UWV have developed the method 'participative work redesign' to support work organizations in their efforts to become more inclusive. This method is being applied in a field experiment in cooperation with a general hospital, the Slotervaart ziekenhuis in Amsterdam. We will present this method and the first experiences with this approach.

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

Jo Lebeer, Petri Partanen, Krisztina Bohacs, Gunvor Sonnesyn, G., Adelinda A. Candeias, Luisa Grácio, Karmen Demeter, Thomas Alexander & Lorna Dawson
University of Antwerp, coordinator of Daffodil Project, INCENA (Inclusion & Enablement), Faculty of Medicine, ELIZA (Primary & Interdisciplinary Care)

Aim

One of the obstacles against inclusive education is the way children with functional impairments are assessed with "classifying diagnostics" based on psychometric test batteries and diagnostic labels. In many countries they are still in special schools. Special needs referrals are increasing, particularly in children from ethnic minorities or socio-economical deprivation. The DAFFODIL project (Dynamic Assessment of Functioning and Oriented at Development and Inclusive Learning), a consortium of 8 partners in 6 European countries and a United Kingdom Overseas Territory in the Caribbean, aims to improve "assessment & coaching" procedures of children with developmental disabilities in order to make it more suitable to inclusion.

Research questions

How do functional and learning assessment systems facilitate or inhibit participation of children with developmental difficulties in (inclusive) education?

Participants and methods

A first phase of the project consisted in researching methods currently in use in Europe and whether or not they meet the needs of professionals and parents. Questionnaires were sent to (medical, psychological, educational) professionals and parents in Sweden, Portugal, Hungary, Belgium, the Netherlands, Romania, Norway and the British Virgin Islands. Interviews and focus groups were organised. In a second phase, expert groups from various disciplines met in focus groups to look for assessment approaches and methods which aim to look at a learner's potential, learning context, functioning, activity and participation. Criteria and a list of recommendations were formulated and subsequently tested via a Delphi method with 74 professionals and parents of 10 European countries.

Results

The European wide survey of currently used assessment methods revealed that static standardized psychometric tests of intellectual, behavior and language functioning(95%) are still dominating the landscape.

While recognizing the utility of functional assessment in obtaining disability benefits (financial, special education resources, recognition and relieve of uncertainty and guilt), there was general dissatisfaction with the mainly negative outlook of reports and deficiency labeling, when it comes to planning adapted and inclusive education. This often leads to a devaluation of the learning capacities of a person with impairments and reinforces their disability situation. The main complaint of teachers and parents was about the poverty of recommendations as how to work with the child. Assessment practice mainly helped to orient the child towards specific school or institutional settings, depending on whether a country has inclusive education practice (Scandinavia and Portugal) or not (other partners), or often leads to poor educational opportunities in activity and participation. Parents advocating inclusive education experience this as an obstacle. Alternatives exist – such as action-oriented assessment, dynamic assessment of learning potential, International Classification of Functioning, portfolio assessment, formative assessment of learning processes, contextual assessment and inclusive consultation – but they are still scarcely used by less than 5%. A list of 14 Guidelines for Dynamic Functional and Inclusive Assessment was agreed upon.

Conclusions

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

3. The capability perspective of impairment and disability: an application among elderly people in Italy

Marco Fuscaldo

Doctoral School in Quantitative Models for Policy Analysis, Catholic University of Milan, Italy

Aim

Over the last years the capability approach has been proposed as a valuable theoretical framework for disability studies (Burchardt, 2004; Terzi, 2005; Mitra, 2006; Trani and Bakshi 2008). Following the capability approach the present paper attempts to examine the intricate relation between the conditions of the body or mind (impairments) and achieved autonomy (disability) among elderly people in Italy. The present study takes into account that impairments may yield a disability through the complex interrelation between the individual's characteristics, her environment and her available resources.

Methods

A two stages Structural Equations Model (SEM) was used. A nested latent structure of impairments was used in order to include disability as a dependent outcome in a causal model, with private resources, personal and external characteristics modeled as exogenous variables. Subsequently, to explore differences in relationship between impairments and disability a multi-group model divided by sub-groups of population was provided. Analyses were based on the second wave of the Survey on Health, Ageing and Retirement in Europe (SHARE).

Results

Considering the entire sample level, the factor of global impairment had the strongest impact on disability. As expected, the residual factors, which measure the extent to which people are exposed to only one type of impairment, had a weaker association with disability. By aggregating the sample into four sub-groups by age and gender, age turned out to be a decisive disabling aspect in the relation between impairments and disability. At the sample level, resources, household composition and area of residence had significant association with disability. However, the aggregation into four sub-groups pointed out large gender and age differences.

Conclusions

The findings have several important implications which provide support for the use of a capability perspective to study disability. It contributes to our knowledge that autonomy of doing the things that we want to do can be used as non-standard indicator of disability. Impairments have distinct effects on disability among sub-groups of population. Finally, resources, personal and external characteristics interact differently in the singular process of achieving autonomy.

Session B. What distinguishes disability studies?

BV-0H20

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

Jean-François Trani and Federica Di Marcantonio

University College London, London, United Kingdom

University of Rome “La Sapienza”, Rome, Italy

This article attempts to compare conceptual models to measure the impact of impairments at the level of individual well-being and capabilities. To obtain more accurate accounts of the multidimensional nature of human life and the freedom of choice of each individual, we based our study on the theoretical framework of Professor A. Sen and followers.

The conceptual model presented in this section aims at describing the theoretical foundations of Sen’s CA in the case of disability, and trying to unpack the links between theory and practice. We also aim at highlighting the limits and strengths of our approach. We introduce a new method to analyse disability with a different perspective than traditional conceptual models. We revisit the application of the CA in the case of disability at two different levels: (i) conceptual; and (ii) analytical.

Furthermore, using data collected from a national survey carried out in Darfur, we consider the two different evaluation spaces in which the CA can be operationalized. We discuss the different methodological implications of the two different evaluation spaces of the CA: functionings and capabilities. Comparison is also made in terms of policy implications and in the overall evaluation of well-being of persons with disabilities.

2. The blind, the sixties and religious care

Paul van Trigt MA, PhD

Student History Department VU University Amsterdam

Since the 1960s the ideal and the practices of the expressive, authentic and reflexive self became very popular in Western societies. Recently some scholars have pointed out how important this ‘subjective turn’ is for understanding in particular the radical changes in the fields of religion, health care and the welfare state in Dutch society. However, little research has been done into how the changes in religion and care were intertwined. Nor into the appropriation of the ideal of self-realization by care-receivers instead of care-givers, whereas the opinion of *disabled* people about self-fulfillment is a very interesting field of research. This paper presents the provisional results of a research project about a religious institute for the blind in the Netherlands. Because the institute is a religious organization that operates in the field of health care, it offers an opportunity to study how changes in religion and care (in connection with the concrete breakthrough of the ideal of self-realization during the sixties) were linked together. Moreover, this case study is a first step in researching whether blind people appropriate the ideal of self-realization or not. The paper also questions the benefits of the (in the Netherlands nearly absent) tradition of disability history.

3. Not Good Enough? Examining the ‘Quality of Life’ of Persons with Disabilities in South Africa

Dr Heléne Combrinck

Centre for Disability Law and Policy, University of the Western Cape, South Africa

Aim

The aim of the paper is to consider the current position of persons with disabilities in South Africa, with specific reference to the notion of ‘quality of life’ as it finds expression in the UN Convention on the Rights of Persons with Disabilities (2006).

Method

The UN Convention on the Rights of Persons with Disabilities (CRPD) guarantees several rights that directly relate to the quality of life of persons with disabilities. These include, for example, the right to live independently and to be included in the community (Article 19) and the right to an adequate standard of living and social protection (Article 28). Given South Africa's progressive constitutional framework and the fact that it has ratified the CRPD and its Optional Protocol, this paper sets out to examine whether the quality of life of persons with disabilities in reality measures up to these human rights standards. Specific emphasis is placed on the right to independent life and community inclusion.

Results

The findings indicate that the experiences of persons with disabilities in South Africa relating to quality of life, and specifically independent life and community inclusion, may vary greatly depending on a number of factors, such as the nature of their disability, whether they live in urban or rural areas and so forth. However, disability remains highly associated with inequality, poverty and unemployment. Persons with psychosocial and intellectual disabilities appear to experience particular discrimination and exclusion.

Conclusions

The paper concludes with a number of recommendations for policy and law reform in order to improve the quality of life of persons with disabilities in South Africa. It further argues that much work remains to be done on the level of awareness-raising and public education in order to realize the right to live independently and to be included in the community, as guaranteed in Article 19 of the CRPD.

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

Auditorium

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

Thiandi M.A. Grooff

Speaker will use a speech output device . The text will be prepared in advance and will be spoken out by a computer and shown via a beamer on a screen to allow the public to read while the text is spoken.

Thiandi Grooff, student at Amsterdam University College, has "a good mind in a strange body". Due to brain damage she has severe difficulty in coordinating her muscles. She is unable to speak, but is still vocal. She could not communicate until she was 14 and was considered severely intellectually disabled until she was able to show, by her writing, that this was not the case.

She thought her life would change considerably once she was able to communicate. She very much wants to be normal and "inside her body" she feels she is. But other people do not perceive her as such.

In her presentation she will go into common views on "normality" and "disability" and the essential need to belong and be different at the same time. She will use her personal experience of exclusion and inclusion in Dutch society and examples of fellow young people less lucky to be fully accepted. As a young girl she once wrote: "Why is everybody afraid of me?"

She is more accepted now that she is a student and author of a book. Still there is discomfort when meeting people. She has clear directives for people who encounter for the first time strange bodies like hers: act normal.

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

Dr. Xavier M.H. Moonen

University of Amsterdam, Amsterdam

Aim

Participatory opportunities within residential care institutions for people with intellectual disabilities are present, but often characterized by lack of pro-activeness or self initiating activities. Aim of our project is to create a participatory culture in residential facilities for care and treatment of children or adults with intellectual disabilities and behavioural problems.

The project is based on a collaboration of the University of Amsterdam (Prof. Dr. G.J. Stams and Dr. X.M.H. Moonen) with two large service providers in the field of people with disabilities, Pluryn Oosterbeek and Koraal Groep Sittard.

Method

A participatory culture is to be implemented in four residential facilities for care and treatment of children or adults with intellectual disabilities and severe behaviour problems. A participatory culture is defined by a basic willingness of the management of the institution to change their institutional policy in accordance with the research-based input from clients. In the project a voluntary group of clients initiate and execute research based on questions they think are important in their lives. They are assisted by a small group of specially trained professionals. After analysing results clients draw conclusions and then present research results in a way they think is appropriate. This could result in a paper but also in a rap-song or video-presentation. Management is obliged to react on the results presented and, if they agree, to collaborate with the client-researchers to implement the results.

The research questions to be answered in the project are whether this kind of participatory research influences the quality of life of the participating children and adults. Furthermore the effects of this collaboration process on staff attitude and staff satisfaction will be established.

Results

Three preliminary short-term research projects are already completed. This resulted in great enthusiasm and the willingness to continue the project. Interesting research was done by the clients which resulted in adjusting some significant procedures in the two participating facilities.

Based on a short time of collaboration our research results suggest however no progress in the measured global self-esteem of the participating children and adults. Although methodological constraints make it difficult to draw overall statistical healthy conclusions. In the presentation methodological questions will be addressed and discussed.

Conclusions

Based on first overall positive results we hope to continue the project on a larger scale in 2012 and to conduct longer and more elaborated research together with all participants.

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

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

1. Dept. of ENT / Audiology, EMGO+ Institute, VU University Medical Center, Amsterdam

2. Dept. of Public & Occupational Health, Research Centre for Insurance Medicine, EMGO+ Institute, VU University Medical Center, Amsterdam

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4. Heliomare Rehabilitation Center, Research and Development, Wijk aan Zee, The Netherlands

There is ample evidence showing that hearing disability has negative effects on daily life functioning, including communication, social life, interpersonal relationships and psychosocial health. The majority of studies examining the association between hearing disability and quality of life included older adults. Although the majority of people with hearing impairment are older than 65 years, a considerable number of younger people are experiencing hearing difficulties as well. Little is known about the effects of hearing impairment in younger age groups. To obtain more insight into the relationship between hearing ability and aspects of life such as work and psychosocial functioning, the National Longitudinal Study on Hearing (NL-SH) (www.hooronderzoek.nl) was set up.

Hearing ability was assessed using the National Hearing test over the Internet. A total of 1511 adults, aged 18-70 years, participated. This group comprised both normally hearing and hearing impaired adults. Questionnaires were used to assess psychosocial health (distress, depression, anxiety, somatisation, loneliness) and workplace characteristics (job demands, job control, need for recovery).

Regression models showed significant adverse associations between hearing status and distress, somatisation, depression and loneliness. Different age groups exhibited different associations. An additional analysis among participants being active in the workforce (N=926) revealed a significant association between hearing status and need for recovery after work, poorer hearing leading to an increased need for recovery.

The findings highlight the specific restrictions of hearing impaired adults younger than 70 years. Implications are discussed.

Session D. Multi Cultural Perspectives on Quality of Life

BV-0H21

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

Patrick Devlieger

In this paper, I consider women’s leadership as a significant actor that stands out in the analysis of Special Olympics as an actor network in Paraguay. This analysis is part of a study of Special Olympics in four countries, namely Namibia, Paraguay, Uzbekistan, and Thailand. However, it was only in Paraguay that women’s leadership that has grown from the experience of being a mother of a child with mental disabilities has been so prominent.

I will review the experiences of three women, all mothers of a mentally disabled child, and explicate their narratives. First, I will retell their stories, and dwell on the creative urge to exercise roles of leadership. This urge is often based in a negative experience, expressed as the need ‘that this does not happen again’. Second, I will refer to the expanded horizon that leadership roles created in Special Olympics for these women. Third, I will refer to the cultural understanding of ‘friends’ in the Paraguayan context. To conclude I will argue that women’s leadership in Paraguay can be understood as based in the local and global social experience of Special Olympics, in the authenticity of the experience, and in the particularities of Paraguayan culture.

2. On how blind photographers suggest a fourth way of inhabiting and approaching “disability”

Benjamin Mayer-Foulkes

Institute of Critical Studies, Mexico

On the basis of fifteen years of involvement with blind photographers, and a reading of Jacques Lacan’s propositions concerning his “Four Discourses” (1968-69), I wish to suggest there are four overall ways of inhabiting and approaching “disability”. Broadly, these can be characterized as Religion, Science, Art, and Psychoanalysis. Each of them entails a certain *quality* of life insofar as they consist in social bonds, and therefore imply various possible configurations of power, knowledge and experience.

Whilst we are amply familiar with the ethos of the first three (Religion, Science and Art), beyond the known forms of psychoanalytic clinical and critical work, as regards “disability” the fourth way (Psychoanalysis), *qua* social bond, remains largely unexplored. Yet the sightless practice of writing with light (*photo-graphy*) provides a commanding example of the nature and fruitfulness of this fourth way. Notwithstanding the character of their artistic projects, the very activity of blind photographers interrogates a host of received ideas about blindness and the image, and clears the way for novel forms of experimenting blindness personally, and appraising it socially.

Thus, beyond ocular impairment as such, blind photographers suggest scenarios related to the wider *being* of “disability” in Psychoanalytic key. Whilst generally associated with a lack, “disability” always involves a paradoxical surplus of psychic, cultural and social capital whose ultimate power —and traditionally perceived threat— is to unveil the artificiality and fragility of social “normality”.

The horizon pertaining to this fourth way of inhabiting and approaching “disability” opens a wide array of theoretical and historical questions, whilst allowing at the same time for innovation in policy and practice. For instance, cultivation of the visual arts can, and should be promoted amongst the blind. Conversely, the blind can, and should be taken in by centres of visual learning focused on design, photography, art, video, animation, cinema, etc. Not in the name of “integration”, but in an effort to alleviate that most perilous form of blindness, so common amongst the sighted: *blindness to blindness itself*.

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

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People labelled as intellectually disabled have lately become the main target group in the claim for social inclusion. Discourses of human rights and changes in local policies, linked to the improvement of quality of life, proliferate in the disability movement and the government's agenda. However, when exploring the intimate life of the individuals concerned and their families, inclusion seems to display a different narrative. Relationships, and specifically the politics of friendship, appear to be superficially considered in the discussion about building inclusive networks to improve the quality of life of those individuals. Drawing on the experience of my three brothers, who have been labelled as intellectually disabled and a sister diagnosed with epilepsy, this presentation seeks to bring out some family daily life events and to connect them with the construction of social capital of disabled people. I argue that intimacy and mutuality are the main tools for such a construction. "Getting to know" a disabled person could contribute to a better and profound understanding of what friendship means and the transcendence of that relationship. The argument will be enriched by some examples brought from my work with disabled families from different ethnic backgrounds living in Ecuador.

DISABILITY STUDIES

In Nederland

Programme at a glance

Disability Studies Conference 'Diversity in Quality of Life'

Time	Thursday, December 2	Friday, December 3	Saturday, December 4	Time
9:00		9:00	9:00	9:00
9:15		Registration	Keynote IV <i>Maya Thomas</i>	9:15
9:30		9:30	Keynote II <i>Lennard Davis</i>	9:30
9:45		10:00	Announcement disability journal <i>Maya Thomas & Wim van Brakel</i>	9:45
10:00		10:30	10:30	10:00
10:15		10:30	coffee & tea break	10:15
10:30		11:00	11:00	10:30
10:45		11:00	Keynote III <i>Jackie Leach Scully</i>	10:45
11:00		12:00	12:00	11:00
11:15		Lunch & Postersession odd numbers	Concurrent sessions IV A: BV-OH19, B: BV-OH20 C: Auditorium, D: BV-OH21	11:15
11:30		Lunch & Postersession even numbers	Keynote V <i>Hans Reinders</i>	11:30
11:45		13:00	13:00	11:45
12:00		13:30	Lunch & Farewell	12:00
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