# Disability Studies International Conference

## 'The Art of Belonging'

October 31 – November 2, 2013

Hotel CASA 400, Amsterdam, the Netherlands

Disability Studies in the Netherlands and VU University Amsterdam

# Colofon

**This conference is organised by:**
Disability Studies in the Netherlands
VU University Amsterdam

**PR & Communication**
For more information about sponsoring, press publications and photo material, please contact:
Irene van Helden, Disability Studies in the Netherlands.
Email: irene.vanhelden@disabilitystudies.nl. Mobile: +31 (0)6-47410429.

**Editor**
Karin van den Bosch

**Image on front page**
*True Colors*, painting by Bert Janssen

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The editor rejects any liability for possible mistakes or any incomplete or otherwise incorrect information contained in this publication, as well as for damages resulting from this publication.

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Furthermore the Organising Committee, the VU University Amsterdam and VUmc Academy 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.

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# Welcome

*At Home*

*It's as if you reach a place,*
*look around and know*
*that you are home.*
*(....)*
*It's as if you knew this place*
*before you ever saw it. Been here*
*since long before you arrived.*

*So at home*

*(Kees Spiering)*

On behalf of the 2nd Disability Studies Conference committee, we warmly welcome you to the city of Amsterdam.

We chose as a conference theme 'The Art of Belonging' giving words and ways to explore an important theme within disability studies. The Art of Belonging is about the tensions between disability experience, the art of living and belonging. Belonging is an ongoing activity where shared spaces of interest and excitement are accessed, negotiated and ultimately occupied.

The conference has 200 participants, coming from all over the world. We are very pleased to have over 100 presentations reflecting a kaleidoscope on the Art of Belonging in papers, posters, workshops, cultural exhibitions and more.
We would especially like to acknowledge all the authors of the abstracts in this book, our many volunteers, colleagues and our funding partners.

We wish all of you lively discussions, shared interests, new friendships and most of all we wish you feel at home!

On behalf of the organising committee,

Minne Bakker
Karin van den Bosch
Wim van Brakel
Mieke Cardol
Jacqueline Kool
Hans Reinders

Alice Schippers,
Chair

## Opening Performance

### ‘*Mother & Son Duets’ by Andrea van Beek*

Andrea van Beek is a singer and singing teacher. She studied violin at the ArtEZ Conservatory and (classical) singing at The Royal Conservatory in The Hague.
Since then she has sung a lot of contemporary music in a theatrical setting. She also toured the world in choirs like Cappella Amsterdam, the Amsterdam Baroque Choir and Collegium Vocale Gent. As a teacher Andrea is working at the University of Arts Utrecht HKU Theatre.
Andrea has 2 sons, Cas (1996-2000) and Jim, who have the same, not diagnosed disease. Jim is 8 years old and severely disabled, he cannot walk, he cannot talk, but he makes beautiful sounds. For the last 2 years Andrea recorded these sounds and now she asks composers to write a duet for her and her son. Together these compositions are giving an image of her son, and all the aspects of their life together.
Andrea will open the Disability Studies International Conference with three of these pieces.

Jim Bouwens- tape
Andrea van Beek- soprano
Gareth Davis- bass clarinet
Ron Ford- composer duet 1
Morris Kliphuis- composer duet 2
Gabor Tarjan- composer duet 3
Xander Straat- coaching & directing

# Organisation

## Organising Committee

Alice Schippers (Chair)
Hans Reinders
Jacqueline Kool
Karin van den Bosch
Mieke Cardol
Minne Bakker
Wim van Brakel

**VUmc Academy course- and congress organisation, Amsterdam, the Netherlands**
Ingrid van de Vegte
Patricia de Waal

**Chair(wo)men Conference**
Guy Widdershoven
Henk Smid
Jenny Goldschmidt
Theo Hooghiemstra

**Buddy Project**
Tamara Visser (coördinator)
Ivan Brown
Jan Boudewijn
Lieke van Heumen

**And all other people who have made this conference possible:**
The people from the DSiN organisation, the volunteers, buddies, people from Casa 400 and everybody else who contributed in his or her own way.

# Information

## General information

**Contact details VUmc course- and congress organisation**
Telephone: +31 (0)20-4448444
Email: paog@vumc.nl

**Opening hours registration desk**
Venue: Casa 400
– Thursday, October 31 12.30-19.30 hours
– Friday, November 1 08:30-17:30 hours
– Saturday, November 2 08.30-14.00 hours

**Registration fees**
The conference fee includes:
- welcome reception on Thursday, October 31
- 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)

**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.

**Evaluation**
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.

**Recordings, photo's or reports**
The conference will be attended by photographers and other press members. If you don't appreciate pictures, recordings or reports, please contact the conference office.

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

**Accessibility**
See the floor plan from Casa 400 for the locations of the accessible toilets.
Casa 400 is fully accessible for wheelchair users.
People who need to rest during the conference or need a breakout room (time out room) can contact the registration desk.

**Language**
The languages at this international conference are spoken English and International Sign.

**Buddy system**
Students will assist participants, if desired, with difficulties with the English language or the academic jargon or offer more general support to people with disabilities (f.i. people with intellectual disabilities, hearing or visual impairments). A one-on-one support is offered. Please contact the registration desk , if buddy support is expedient.

**First aid**
If any participant requires first aid, please contact the main registration desk.

**Lost property**
Enquiries regarding items lost or found can be made at the registration desk or at the main reception desk of Casa 400.

**Mobile phones**
**Please note: Mobile phones must be switched off during presentations and performances.**

**Additional information and contact**
Visit our website http://disabilitystudies.nl/ for additional information. For any questions you may have on the 2nd Disability Studies International Conference 2013, please contact the VUmc Academy course- and congress organization, email: paog@vumc.nl. Website: www.paog.nl.

# Information for international visitors

## Emergency contacts

**European Emergency Number: 112**
Disabled people can use Real-time text to contact 112.
The European Emergency Number 112 is the only emergency number in the Netherlands.
By dialing 112 you can get into contact with the police, fire brigade or ambulance (first you get connected to an operator). Operators can be expected to speak Dutch, English and German. 112 calls from mobile phones in the Netherlands are possible even if there is no SIM card or your prepaid phone card ran out of money. Only dial 112 for serious or life threatening accidents.

**Police (non-emergency): 0900-8844**
If you want to contact the police, but it's not an emergency, dial the national Police number: 0900-8844.

**Tourist Medical Service Amsterdam: 020-5923355**
The Tourist Medical Service Amsterdam provides accessible medical care for guests in Amsterdam. Whether it's lost or forgotten medication or more acute medical care: qualified doctors of the TMS are stand by 24 hours a day. Website: http://touristdoctor.nl/

**Animal ambulance: 0900-0245**
Dutch people care about animals. If you see anything happening to an animal, like a caraccident, please call the Animal Ambulance service in the Netherlands.

## Other helpful contacts

**Visitor Information Centers**
Amsterdam has several Visitor Information Centers:

-Visitor Information Center Central Station
Noord-Zuid Hollands Koffiehuis, Stationsplein 10 (across from Central Station)
Tel: +31 (0)20 702 6000
-Visitor Information Center Schiphol Airport
Schiphol Airport, Arrivals 2 at Schiphol Plaza
Tel: +31 (0)20 702 6000
-Visitor Information Center Leidseplein
Leidseplein 26, 1017 PT Amsterdam
Tel: +31 (0)20 702 6000

**Yellow Pages (in English): 0900-8008**

## Communication

**Mobile telephony**
There are several mobile phone providers in the Netherlands, for example KPN, T-Mobile or Vodafone. Using your mobile phone while driving is illegal, unless you use a hands free set.

**Internet**
Hotel Casa 400 has free WIFI high-speed internet at your disposal all through the hotel.

## Electricity
The voltage in The Netherlands is 220-240 Volts.

## Transportation
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. 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.

**By foot**
You can find city maps on the internet (e.g. https://maps.google.nl/ ). You can also get them at a Visitor Information Center or at your hotel.

**Cycling**
Cycling is the most used form of daily transport in the Netherlands. Riding a bike is convenient and cheap. Throughout the city of Amsterdam, and actually all over the country, there are separate bicycle lanes. You can rent a bike at the Central Train Station or at several local rent-a-bike companies. Bikes are not allowed on Dutch busses and trams. They are allowed on Dutch trains, but if you want to take your bike in the train, you need to buy a special bike ticket before boarding.

**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!

If you want to use the Public Transport in the Netherlands, you need a special Public Transportation card, called 'OV-chipkaart' (Openbaar Vervoer Chipkaart = Public Transportation Chipcard). With this OV-chipcard you can travel by bus, tram, metro and train. There are three types of OV-chipcard: a disposable OV-chipcard, an anonymous OV-chipcard and a personal OV-chipcard. The disposable OV-chipcard is intended for people who do not use the Dutch public transportation system very often, for example tourists. The disposable card has a fixed amount of credit, and is not rechargeable. The anonymous OV-chipcard is reusable. You can (re)load it with credit. You can buy the (disposable) OV-chipcard on board, at several machines and at major public transportation stations.
*Note that you always have to check in and check out with your card!*
*Make sure you always have enough credit on your card when travelling!*
More information: https://www.ov-chipkaart.nl/?taal=en

**Driving**
In the Netherlands you drive on the right side of the road. Trams, busses and cyclists have priority. You are obliged to carry your driving license and car insurance card with you. It's prohibited to use your cell phone while driving, unless you use a hands-free set.

**Taxi**
Amsterdam has many taxi companies. You can find them on the internet, or by calling the Yellow Pages: 0900-8008. The reception of your hotel might also be able to help you. To order taxis for disabled people we would like to direct you to the registration desk.

## 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. Cash machines can be found at banks, post offices, supermarkets, airports and along the street.

## 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.

You're advised to go to one of the Visitor Information Centers for more information about Amsterdam or the rest of the Netherlands.

## Accommodation

There is a quota of hotel rooms available at the conference center Casa 400 in Amsterdam. There are several other options in Amsterdam, including B&B's and (budget) hotels. Please note that accommodation is not included in the registration payment. Each participant shall book and pay for their accommodation themselves. For more information you can visite the website www.toegankelijkamsterdam.nl (in Dutch or English).

## Travel

The Hotel and Conference center Casa 400 in Amsterdam is close to Schiphol International Airport and the city center. There are excellent rail, tram and bus connections between Casa 400 and the airport. Information on wheelchair accessibility of the Amsterdam public transport and accommodation you can also find at the website www.toegankelijkamsterdam.nl.

# Information for poster presenters

The poster presentation is an effective way to communicate your research or project to colleagues. Below are some detailed instructions concerning your poster presentation.

## Schedule

**Presentation date, time and place**
The poster presentations take place on Friday November 1, 2013 from 11.45 hours till 12.15 hours. Location: Vide/Balcony at hotel Casa 400, Eerste Ringdijkstraat 4, 1097 BC Amsterdam.

Use your poster to attract your audience for discussion, not to present complex details of methods and results.

After the poster presentation session, please leave a note on your poster board as to where you can be reached in case someone wishes to discuss your research or project further.

**Poster set up**
Poster presenters are expected to mount their posters on the allocated boards in the poster area on **Friday November 1 between 8.30 am and 9.00 am.**

Each board will be numbered on the upper left corner. Be sure you place your presentation on the board number for your poster that appears in the final program that you will receive at the conference.

Pushpins and other materials are available at the registration desk.

A volunteer will be present to help you with the poster set up.

**Poster removal**
All posters must remain on the display the entire day. Do not remove your poster before 21.00 hours on Friday. If you want to remove your poster on Saturday, that's also possible. In that case, please remove your poster on **Saturday November 2 between 13.30 and 14.30 hours**. Unclaimed posters will be discarded after this time.

## Handouts

Authors are encouraged to provide handouts, e.g., preprints, extended abstracts, copies of poster panels, etc.

## Further information

The following website provides some useful information on preparing effective posters for conference presentation: http://www.phcris.org.au/infobytes/poster_presentations.php

# Information for oral presenters

**Presentation date and time**
You can find the presentation date and time in the Conference Programme.
Please make sure to be present in the correct room (see Programme) at least 15 minutes before the start of the session.

**Structure of the symposia**
The duration of your presentation is 15 minutes. Three presentations together make a symposium. Immediately after your presentation, the audience has 2 minutes time to ask some *clarifying* questions. Substantive questions and discussion need to be suspended until after the last presentation. After the last presentation there is time for a plenary discussion about the topic of the symposium. The audience as well as the presenters are welcome to join the discussion, of course. We hope that all symposia have a lively substantive discussion after the presentations!

Schedule:

*15 minutes* presentation (three times)
*2 minutes* clarifying questions (three times)
*20 minutes* plenary discussion at the end

**Audiovisual equipment**
The following audiovisual equipment will be available in the lecture rooms:
Conference rooms (UVA1, Erasmus 1 & 2): handheld wireless microphone, audio system, laptop, projection screen. Extended meeting rooms (Stellenbosch, Oxford & Sorbonne): laptop, audio system, beamer & smart board.

**Audience**
The audience can consist of people with or without a (visible) disability. Not all people have an academic (scientific) background. We recommend making your presentation as accessible as possible for a diverse audience. Depending on the size of the room the audience can consist of up to 40 people, even more in the main lecture room.

**Handing over your presentation**
Please hand over your PowerPoint presentation to one of the staff members at the registration desk.

**Timeschedule handing over your presentation:**
For those presenting **before** lunch: between 7.30 – 8.30 am or the day before during tea break.
For those presenting **after** lunch: during the first coffee or lunch break.

**Speaker ready room**
The speaker ready room is a place where all oral presenters can prepair their presentation. The speaker ready room is presumably located next to the registration desk. Ask one of the staff members on the conference day for final details.

# Information for moderators

Moderators have two important tasks:
1) Time management
2) Give a substantive input in the discussion, if necessary.

**Time management**
The symposia have a certain structure: every presenter has 15 minutes for his/her presentation. Afterwards the audience has two minutes time to ask some *clarifying* questions. After the last presentation there is 20 minutes time for a plenary discussion about the topic of the symposium. It might be useful for moderators to make agreements with the presenters about the time management.

**Regarding the discussion**
Of course we hope that all symposia will have a lively substantive discussion after the presentations. However, it might be possible that the discussion needs some input. This is something the moderator could facilitate, for example by asking questions or posing a statement/proposition based on the themes of the presentation. Moderators should also make sure that everybody gets the possibility to give his/her opinion.

Please make sure to be in time for the symposium you moderate.
Please read carefully the abstracts of the symposium you moderate, so you will be able to give input to the discussion.

## Information about the programme

The theme of the Disability Studies International Conference is '*The Art of Belonging'*, a focus that traverses the tensions between disability experience, the art of living and belonging. The *art of belonging* is a topic that is open to individual perspectives as well as to the exchange between personal and public perspectives. During the conference this topic will be addressed in academic and non-academic ways. Disciplines as diverse as architecture, arts, political theory, public health, theology and history will be present. We expect the conference presentations to be as diverse as the art of belonging itself!

**Program**
The Program starts on Thursday October 31, with the opening of the conference and a keynote lecture. Keynote speakers will address the conference on Friday and Saturday morning, November 1st and 2nd. Friday and Saturday morning there will be four concurrent sessions with both invited and free papers. The Closing ceremony on Saturday November 2 with Jetta Klijnsma, State Secretary for Social Affairs and Employment.

**Goals**
The conference goals are to promote the inclusion of Disability Studies in academic research agendas and curricula in The Netherlands, to facilitate the exchange between academia (scientists and students), persons with disabilities and their organizations, and public policy making agencies.

**Audience**
The conference will bring together about 200 people from various communities and nationalities. Apart from persons with disabilities and their organizations it will include (international) researchers from research centers and institutes, students, professionals, administrators and policy makers.

**Streams**
To help you find your way in all this variety we bundled presentations in streams. These are the following streams: *Social Inclusion & Representation, (Family) Quality of Life, Empowerment & Environment, Inclusive Employment, Friendship, Inclusive Methods, Workshops, Inclusive Education,* and *Public Policy & Rights*.

**Social programme**
You will have several opportunities to meet your colleagues and friends in informal settings at the conference and at the social events: at the welcome reception, the conference dinner and of course at the coffee and tea breaks and lunches.

# Cultural programme

The cultural programme consists of the music performance 'Mother and Son Duets' by singer Andrea van Beek at the opening of the conference; the performance by Art Loca; an Art Exhibition by Bert Janssen and Cartoon Exhibition by GRIP foundation; and a cultural programme by keynote speaker Simi Linton.

## Art Loca - performance & short film

Art Loca uses performing arts, such as theatre, music and dance, to help increase the artistic and personal development of people with intellectual disabilities so they can participate more easily in society.

Art Loca is based on three principles: **Art, love and care.**

**Art** as a means and as a purpose,
**Love** for people and our profession,
**Care** for caring and diligence in working with people.

When in society people with and without disabilities live and work separately, it may lead to prejudice and there may be less value assigned to the one that is different: unknown makes unloved and misunderstood. Therefore Art Loca brings people with and without intellectual disabilities together. Art Loca works with a wide range of groups, such as schools and companies and makes theatre on location.

*Contact and information:*
Art Loca, Kerkgracht 111, 1354 AK Almere, the Netherlands
Contactperson: Mieke van Dijk
Mobile: +31 (0)6-41364191, email: info@artloca.nl, website: www.artloca.nl

## Art Exhibition by Bert Janssen

During the conference art works of the artist Bert Janssen will be presented in the foyer and balcony of Casa 400. One of his paintings, titled *True Colors*, is used for the logo of the conference.

**About the artist Bert Janssen**
Paint, cement, clay, sand, soil, water, fire and ashes... Bert Janssen experiments with raw materials, colors and structures. He constantly positions himself as part of the creative process. He is gripped by the process of growth and proliferation until the moment he transcends this process and 'sees that it is good'.

*Contact and information:*
Materieschilderen kunstverhuur, Verkoop en Workshops, Amsterdam, the Netherlands.
Telephone: +31 (0) 639790774, email: info@materieschilderen.nl, website www.materieschilderen.nl.

## Cartoon exhibition – GRIP ( Belgium)

More then twenty Cartoons will be showed in Casa 400. It's a special exhibition about Disability & Human Rights made by Belgium cartoonists. Website: www.gripvzw.be.

## Buddy project

Everyone has the right to participate, everyone counts, but belonging is more than a right. For quality of life people need to gain ‘the art of living’. This is something people learn and develop throughout their lives, by personal experiences and social participation. The point is that people with and without disabilities find their place and relate to each other, without having to ‘bend over backwards’. Belonging demands continuous activity, sometimes political.

The conference has a cross- disability perspective. Not the exception, but the social perspective of the limitation is important. People with and without disabilities and their network will participate in the conference. Participants have a variety of academic and non - academic backgrounds from different disciplines. Such an approach fulfils a need, as past experience at the first congress has shown.

The conference has a twofold objective. First, we aim to build bridges between the academic world and everyday practice. The diversity of disciplines and a variety of international participants allows exchange of knowledge and insights. Secondly, we want to bring the personal and the social worlds together by meeting each other.

DSiN considers it important to the 2nd International Conference that it is optimally accessible (in a material sense, but also in terms of content and knowledge). The buddy project fulfils a need for people to have connections that they wouldn’t normally make. People with and without disabilities meet and learn from each other.

The buddy program will be in addition to a facilitating function (such as translation, interpreting, simplify or guide) and also consist of a training and workshop session at the conference itself.

The buddy’s participating in this project will be trained by and will earn a certificate issued by the Academy for Teaching, Learning and Research, a branch of the International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD).

The buddy project is sponsored by Instituut Gak (www.instituutgak.nl).
Instituut Gak is a fund that provides grants and stimulates social investments in the areas social security, education and employment.

## Closing ceremony

**With Jetta Klijnsma, State Secretary for Social Affairs and Employment**

The Disability Studies International Conference will have a special closing ceremony with the Dutch State Secretary for Social Affairs and Employment Jetta Klijnsma. She will share her view of disability studies.
Since November 2012 Jetta Klijnsma has been State Secretary for Social Affairs and Employment, dealing with unemployment insurances (partial), equality, long-term unemployment, poverty, health and safety. She has worked in various capacities for the parliamentary party of the Dutch Labour Party (PvdA) and for the municipality of The Hague, including heading the list of PvdA candidates in the 2006 municipal council election. Ms. Klijnsma has also been involved in many civil society organisations related to social care and welfare, including the Liliane Fund, the Stichting Korrelatie helpline and the Start Foundation.

# Venue

The conference takes place at hotel Casa 400.

*Address:*
Eerste Ringdijkstraat 4
1097 BC Amsterdam
Tel. +31 (0)20 6651171
http://www.hotelcasa400.nl/en/index.html

**Hotel and conference center Casa 400 in Amsterdam**

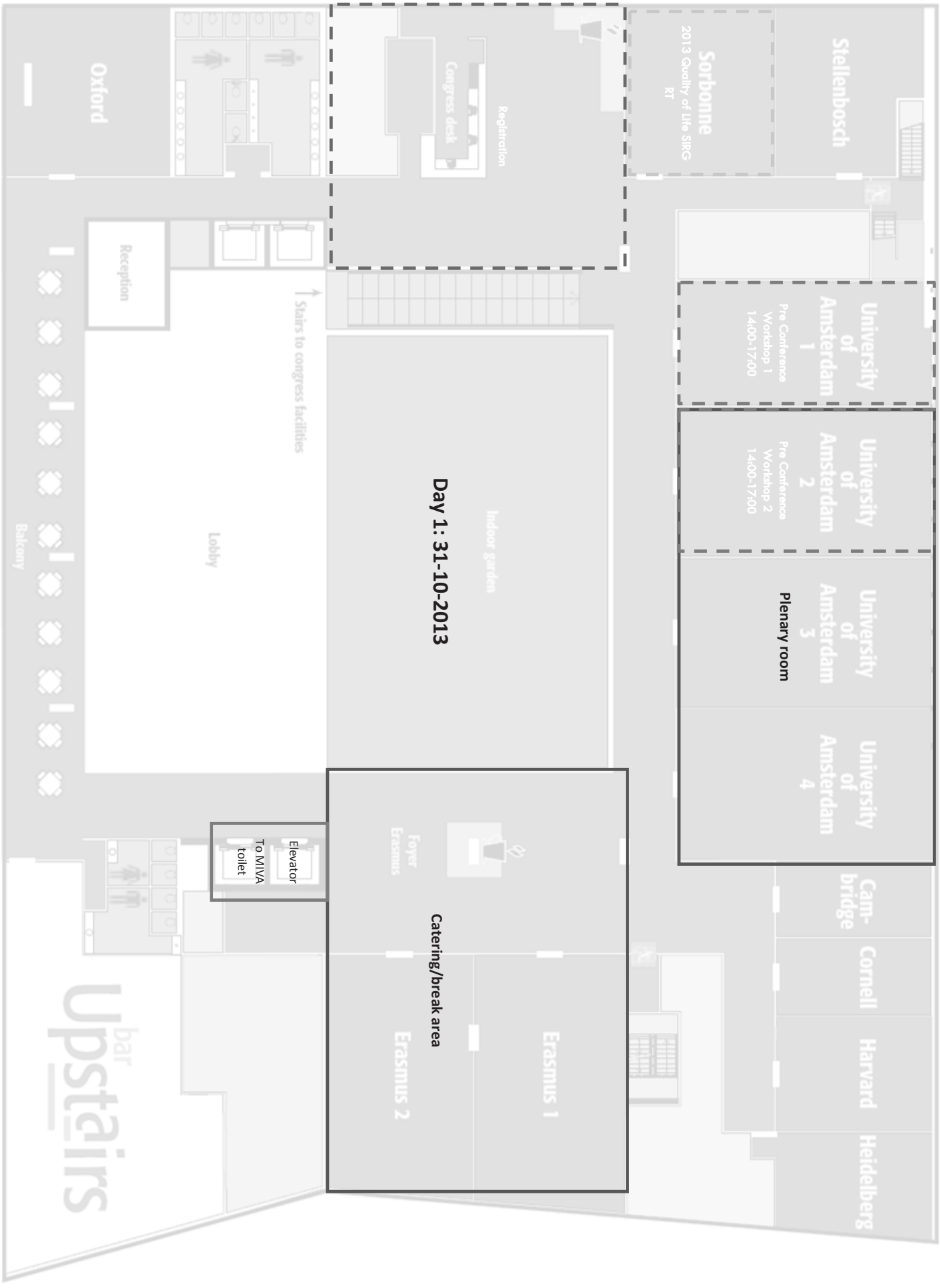
The conference will be held at the Hotel and conference center Casa 400 in Amsterdam, close to Schiphol International Airport and the city center. There are excellent rail, tram and bus connections between Casa 400 and the airport.

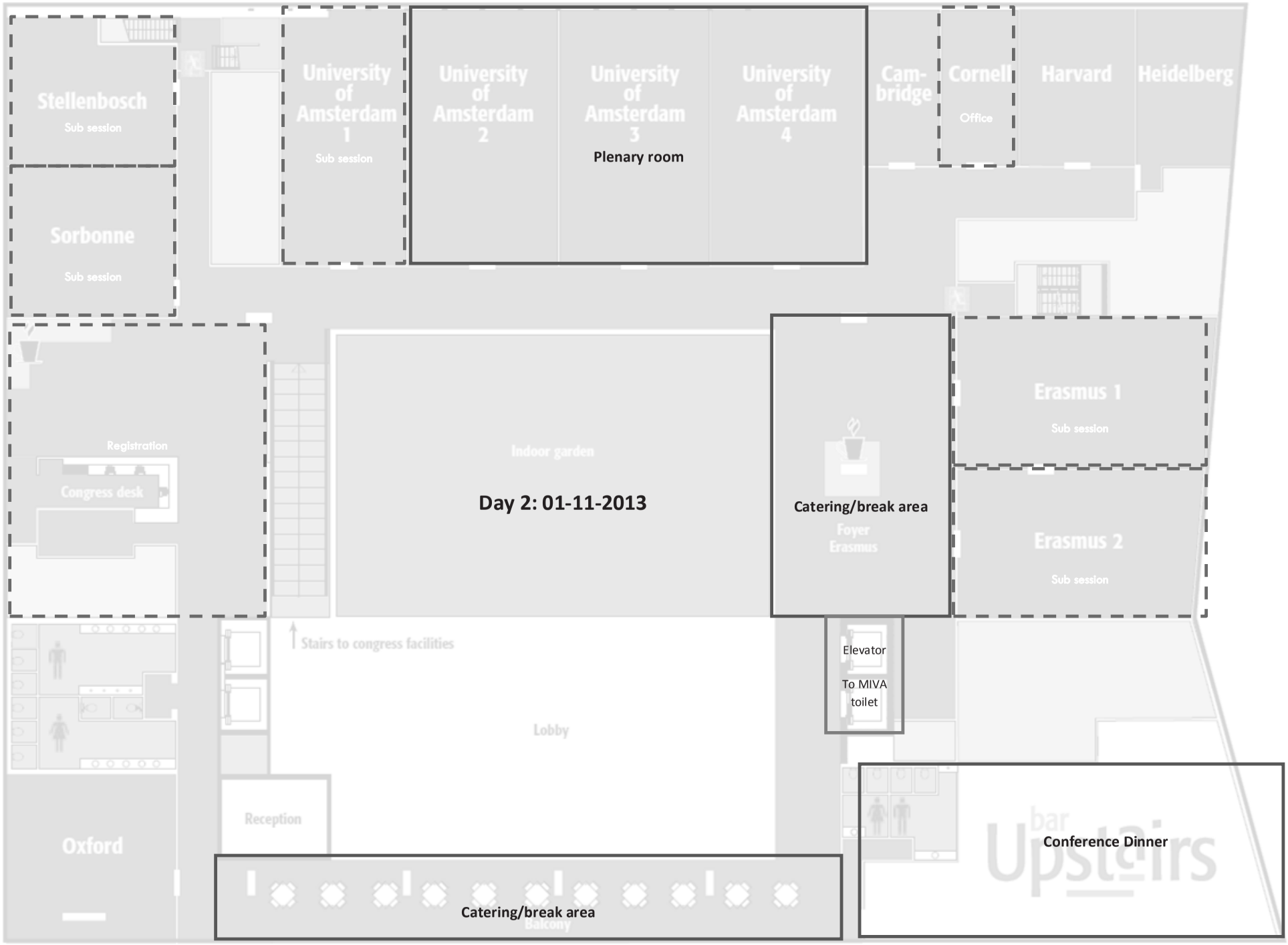
Hotel Casa 400 is fitted with modern conveniences with her spacious, comfortable hotel rooms, Restaurant Circles, Bar Upstairs, 13 conference rooms, an indoor garden, underground car park and free Wi-Fi throughout the whole hotel.

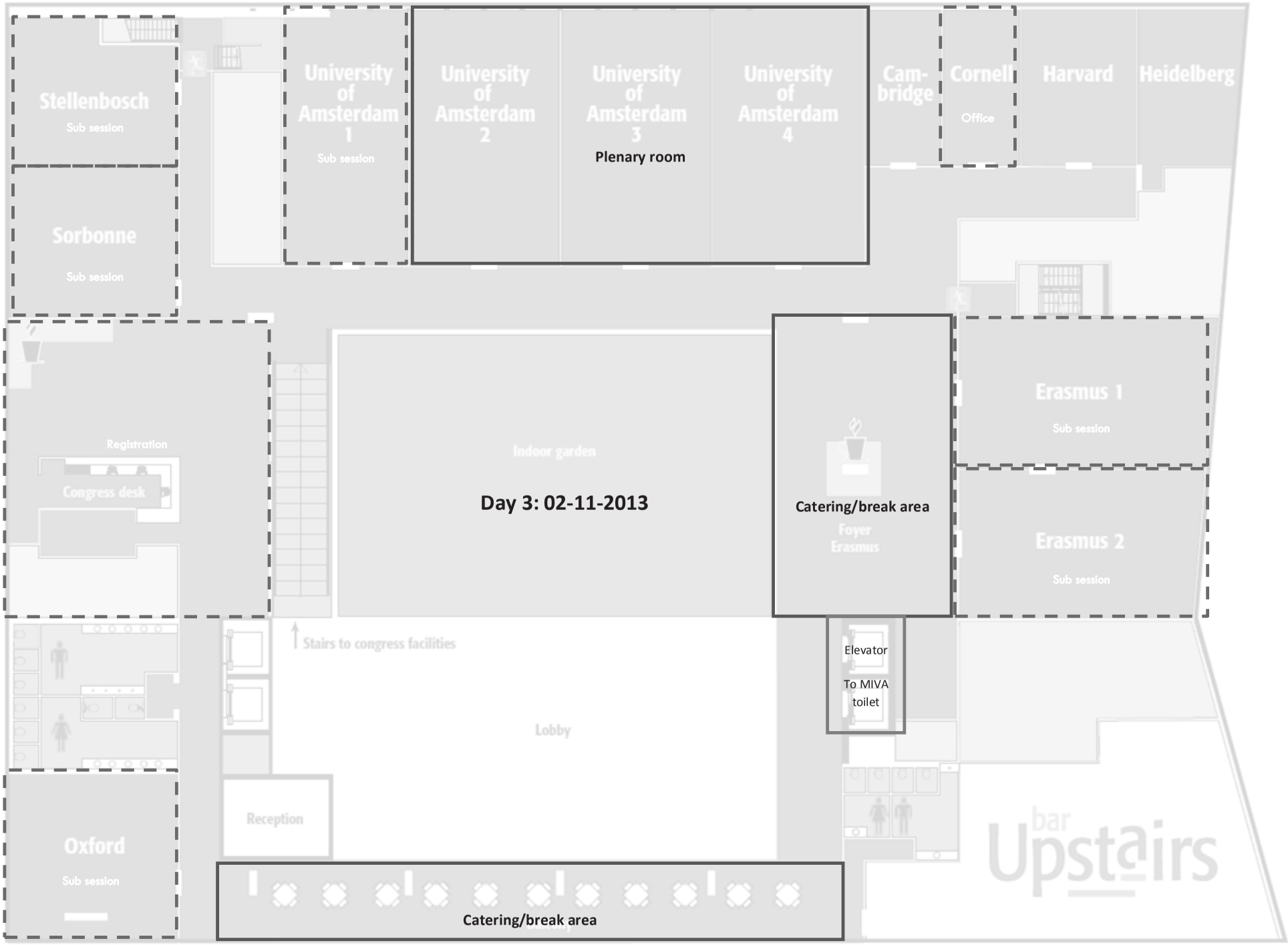
Hotel Casa 400 Amsterdam officially opened in the spring of 2010. By the end of the year, the hotel received the Best Hotel Concept of the Year award, and the Golden Green Key. Besides, Hotel Casa 400 also received the HotAm award for most exciting hotel development in Amsterdam.

Hotel Casa 400 is convenient located within the ring road of Amsterdam in the Amstel district. You will have everything in arm's reach: the public transport will take you to the heart of Amsterdam within 9 minutes, the Amsterdam Amstel station is a mere three minute walk away from the hotel and the ring road A10 can easily be reached.

## Floorplan CASA 400




Stellenbosch
Sub session
Sorbonne
Sub session
University of Amsterdam 1
Sub session
University of Amsterdam 2
University of Amsterdam 3
Plenary room
University of Amsterdam 4
Cam-bridge
Cornell
Office
Harvard
Heidelberg
Registration
Congress desk
Indoor garden
Day 2: 01-11-2013
Catering/break area
Foyer Erasmus
Erasmus 1
Sub session
Erasmus 2
Sub session
Stairs to congress facilities
Elevator
To MIVA toilet
Lobby
Reception
Oxford
Catering/break area
Balcony
bar Upstairs
Conference Dinner


Stellenbosch
Sub session
Sorbonne
Sub session
University of Amsterdam 1
Sub session
University of Amsterdam 2
University of Amsterdam 3
Plenary room
University of Amsterdam 4
Cam-bridge
Cornell
Office
Harvard
Heidelberg
Registration
Congress desk
Indoor garden
Day 3: 02-11-2013
Catering/break area
Foyer Erasmus
Erasmus 1
Sub session
Erasmus 2
Sub session
Stairs to congress facilities
Elevator
To MIVA toilet
Lobby
Reception
Oxford
Sub session
Catering/break area
bar Upstairs

# Programme

**Thursday, October 31**
Chair: Jenny Goldschmidt

**12:30-19.30** **Registration**

**14:00-17:00** **Pre-conference Workshops IASSIDD Academy**
**Concurrent Sessions:**

- Workshop 1: *Dementia and Age-Related Decline in People with Lifelong Disabilities*
  M. Janicki & R. Lucchino
  **UvA 1**
- Workshop 2: *Quality of Life Applications in Education & Families: Challenges and Solutions*
  R. Faragher & N. Zuna
  **UvA 2**

**18:30-19.00** **Coffee & Tea Break**
**Foyer Erasmus**

**19:00-20:00** **Opening Conference**
**Music**
*Mother and Son Duets*
Andrea van Beek
**Main Lecture Room**

**20:00-21:00** **Keynote Lecture I**
*Two Roads Diverged: Choreographing a Sense of Belonging for All*
Ann Turnbull
**Main Lecture Room**

**21:00-21:30** **Reception**
**Foyer Erasmus**

**Friday, November 1**
Chairs: Theo Hooghiemstra & Guy Widdershoven

**08:30-17:30 Registration**

**09:15-10:00 Keynote Lecture II**
*Sibling's Relationships and the Art of Belonging: personal experience and ethics of recognition*
Beatriz Miranda Galarza
**Main Lecture Room**

**10:00-10:30 Coffee & Tea Break**
**Foyer Erasmus**

**10:30-11:45 Concurrent Sessions I**

- **Stream Social Inclusion & Representation**
  **Symposium: Belonging: Strengths & Barriers I**
  Moderator: G. van Hove
  1. H. Kröber *Persons with ID, poverty and inclusion. A Dutch Perspective* (O-01)
  2. E. de Schauwer *Art of Portraiture* (O-02)
  3. A. Brummel *Community-based social inclusion of citizens with mental disability and citizens with psychiatric problems; a case study at three different districts in Nijmegen* (O-03)

  **UvA 1**

- **Stream (Family) Quality of Life**
  **Symposium: Family Quality of Life**
  Moderator: A. Schippers
  1. I. Brown (D. Roth) *Family Quality of Life: International Comparisons of 18 Studies in 14 Countries* (O-16)
  2. L. van Heumen *Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families* (O-17)

  **Erasmus 1**

- **Stream Empowerment & Environment**
  **Symposium: Belonging through Performance**
  Moderator: M. Bakker
  1. Y. Kelders *Vulnerability and the disabled body. Getting a sense of belonging through the other* (O-24)
  2. H. van der Horst *Technical aids, aesthetics and the mediation of belonging* (O-25)
  3. S. Hilberink *Agency in the 21st century: the emperor's new clothes* (O-26)

  **Main Lecture Room**

- **Stream Inclusive Employment**
  **Symposium: Participation through Paid Work**
  Chair: W. van Brakel
  1. K. van Brakel *Can't do it on their own; The work participation of young disabled persons in the Netherlands* (O-33)
  2. B. Cornelius *High prevalence of early onset mental disorders among long-term disability claimants* (O-34)
  3. T. Araten-Bergman *Employment, Social Capital and Community Participation among Israelis with Disabilities* (O-35)

  **Stellenbosch**

- **Stream Friendship**
  **Symposium: Reciprocity & Intimacy**
  Moderator: M. Cardol
  1. M. Hermsen *The possibility of cultivating reciprocal relationships* (O-42)
  2. N. Frielink *The applicability of motivational interviewing among people with mild to borderline intellectual disability; a self-determination theory perspective* (O-43)
  3. K. van den Bogaard *Development of an evidence based training focused on sexuality and sexual abuse of people with intellectual disabilities* (O-44)

  **Sorbonne**

- **Stream Inclusive Methods**
  **Symposium: Designing Methods for All**
  Moderator: T. Abma
  1. S. Woelders *One for all, all for one – working together for optimal participation of people with intellectual disabilities/Down syndrome. A connection between disability studies and patients participation perspective* (O-57)
  2. M. Herps *Individual support planning: perceptions and expectations of people with intellectual disabilities in the Netherlands* (O-58)
  3. T. Maillard *A self-advocate's right to belong as a form of resistance in higher education and disability studies* (O-59)

  **Erasmus 2**

**11:45-12:15 Poster Presentations**

1. S. Kef *Community perspectives on increasing social participation of persons with visual impairments* (P-1)
2. N. Baqués *Family Needs in Spain* (P-2)
3. T. Nijhoff *Disabling barriers, restrictive contextual factors for people with disabilities* (P-3)
4. D. Bratkovic *Self-Advocates' Evaluation of the UN Convention on the Rights of Persons with Disabilities (2006) Implementation* (P-4)
5. S. Reker *The art of belonging and social space – How does the Convention on the Rights of Persons with Disabilities challenge society and service provision?"* (P-5)
6. M. van den Wildenberg *Inclusive architectural design. Involving impaired people in the design process* (P-6)
7. M. Nossin *Every child belongs in inclusive education. Together with parents and children in search of inclusive learning environments* (P-7)
8. K. Pancocha *Disability experience in postsocialist context: social participation as a concept and as a tool* (P-8)

**Vide/Balcony**

**12:15-13:15 Lunch**

**Foyer Erasmus, Vide & Bar upstairs**

**13:15-14:30 Concurrent Sessions II**

- **Stream Social Inclusion & Representation**
  **Symposium: Belonging: Strengths & Barriers II**
  Moderator: M. Cardol
  1. J. Clapton *Precarious Belonging: Chronic Homelessness and People with Impaired Decision Making Capacity* (O-04)
  2. R. Hendriks *Sharing Limburg – Including people with dementia in a process of cultural reproduction* (O-05)
  3. M. Pater *Autism and the art of communication* (O-06)

  **UvA 1**

- **Stream (Family) Quality of Life**
  **Symposium: Family & Disability Issues**
  Moderator: A. Schippers
  1. N. Zuna *Understanding Disability Belief Systems: Family Perspectives and Impact* (O-18)
  2. E. de Schauwer *Working with parents of children with a disability – a continuing dialogue* (O-19)
  3. B. Piškur *Parents' concerns about their child's doing, being, becoming and belonging* (O-20)

  **Erasmus 1**

- **Stream Empowerment & Environment**
  **Symposium: Adapting the Environment**
  Moderator: J. Kool
  1. S. Flynn *Avatar: Ableism and Normalization* (O-27)
  2. M. Hoogsteyns *How to turn technical aids into social mediators?* (O-28)
  3. P. van der Kaa *Creating a positive view* (O-29)

  **Main Lecture Room**

- **Stream Inclusive Employment**
  **Symposium: The Essentials of Belonging: Inclusive Employment**
  Moderator: K. Vornholt
  1. G. van Ruitenbeek *Experiences with the Method 'Inclusive Redesign of Work Processes'* (O-36)
  2. K. Vornholt *Acceptance of People with Disabilities at Work. A literature review and validation of a newly developed questionnaire* (O-37)
  3. P. Nelissen *The Building Blocks of an Inclusive Climate* (O-38)

  **Stellenbosch**

- **Stream Friendship**
  **Symposium: Hybrid Spaces of Belonging**
  Moderator: G. Widdershoven
  1. C. Shpigelman *Social media and people with intellectual disabilities* (O-45)
  2. H. Meininger *Inclusion as Heterotopia: Spaces of Encounter Between People With and Without Intellectual Disability* (O-46)
  3. G. Dingler *Focus on Friendship; (dialogue) conversations about social relations with secondary schools and their students with autism* (O-47)

  **Sorbonne**

- **Workshop: Accessible Society I**
  Moderator: T. Visser
  H. Kroon *The Power of Valued Social Roles* (O-60)

  **Erasmus 2**

**14:30-14:45** **Short film**
Art Loca

**14:45-15:00** **Videopresentation**
*What makes Belonging an Art?*
Hans Reinders
**Main Lecture Room**

**15:00-15:30** **Coffee & Tea Break**
**Foyer Erasmus**

**15:30-16:45 Concurrent Sessions III**

- **Stream Social Inclusion & Representation**
  **Symposium: Representation**
  Moderator: J. Kool
  1. M. Waltz *When "awareness" becomes stigma: Representations of autism in charity campaigns and the media, and their impact on people with autism* (O-07)
  2. K. de Munck *Who Makes the Portrait? Whose Portrait is it? Portraiture as Interplay between Participant, Portraitist and Audience* (O-08)
  3. S. Banens *"Does my daughter really belong in our society?"* (O-09)

  **UvA 1**

- **Stream (Family) Quality of Life**
  **Symposium: Belonging & Quality of Life**
  Moderator: N. Zuna
  1. R. Turnbull *Family support and public policy* (O-21)
  2. A. Žic Ralić *The application of the oriental dance to persons with intellectual disabilities* (O-22)
  3. W. Buntinx *What can positive psychology contribute to enhancing the quality of life of persons with (intellectual) disabilities?* (O-23)

  **Erasmus 1**

- **Stream Empowerment & Environment**
  **Symposium: Adapting the Environment II**
  Moderator: G. Van Hove
  1. M. Sarmiento *The User-Initiated Design Phenomenon in Stroke Survivors: Adapting Inaccessible Environments* (O-30)
  2. M. Koutská *Culture for Everybody? Museums and Galleries Accessible for Deaf Pupils in the Czech Republic, France and Sweden* (O-31)
  3. S. van Hal *Accessibility for people with different kinds of disabilities in community organizations in Amsterdam* (O-32)

  **Main Lecture Room**

- **Stream Inclusive Employment**
  **Symposium: Work as Catalyst for Belonging**
  Moderator: W. van Brakel
  1. T. van Wieren *Autism Spectrum Disorders and Intellectual Disabilities: Private-Sector Workplace Discrimination in the U.S.A.* (O-39)
  2. E. de Vos *Active inclusion of young people with health problems or disabilities in 11 EU-Member States* (O-40)
  3. C. Aarnoutse *Key elements in transition from school (VSO) to employment: a survey and a new approach* (O-41)

  **Stellenbosch**

- **Stream Friendship**
  **Symposium: Belonging 'Inside-Out'**
  Moderator: H. Meininger
  1. J. McDonagh *Friendships: a personal story of formation, loss and maintenance* (O-48)
  2. G. Bos *Hear, look, touch. Stories about self-transforming experiences in proximity of, and encounters with other bodies* (O-49)
  3. J. Bouwer *Towards a prototypical conceptual model for the interrelations among disability, belonging and leisure* (O-50)

  **Sorbonne**

- **Stream Inclusive Education**
  **Symposium: Belonging through Education I**
  Moderator: B. Miranda Galarza
  1. A. Sakellariadis *Looking through a new lens: educational status quo and the social model of disability* (O-66)
  2. D. Roth *Preschool children's attitude-perception towards children with disability* (O-67)
  3. T. Grooff *Can disabled children in the Netherlands get access to (mainstream) education by litigation in international courts and in this way to the status of belonging?* (O-68)

  **Erasmus 2**

**17:00-18:00** **Keynote Lecture III**
*Disability and the Creative Art of Belonging*
Simi Linton
**Main Lecture Room**

**18:30-20:30** **Conference Dinner**
**Restaurant Casa 400**

**Saturday, November 2**
Chair: Henk Smid

**08:30-14:00 Registration**

**09:00-09:45 Keynote Lecture IV**
*Reflection 2nd Disability Studies International Conference 2013*
Robert Maier
**Main Lecture Room**

**09:45-11:00 Concurrent Sessions IV**

- **Stream Social Inclusion & Representation**
  **Symposium: Inclusive Relations**
  Moderator: M. Bakker
  1. J. McDonagh *Transitions: a journey through child-based health services to adult services - a personal account* (O-10)
  2. M. Nossin *iSupporter* (O-11)
  3. I. van de Putte *"Andreas is a child in MY class!" Developing a support concept for teachers while working with diverse students* (O-12)

  **UvA 1**

- **Stream Public Policy & Rights**
  **Symposium: Social Network and Public Policy**
  Moderator: B. Miranda Galarza
  1. H. van Haaster *Financial incentives for independent living* (O-72)
  2. T. Makaradze *Needs and Challenges of Care Givers of Adolescents with Developmental Disabilities in Georgia* (O-73)
  3. P. van Trigt *Historicizing the art of belonging. Disability, activism and social science in the United Kingdom and the Netherlands since the 1960s* (O-74)

  **Erasmus 1**

- **Stream Participation**
  **Symposium: Participation: Belonging Together**
  Moderator: M. Cardol
  1. M. Cardol *Participation in terms of belonging to this AND that* (O-78)
  2. L. Claes *"Longing to belong." Spaces of (non-)belonging in the life trajectories of people with intellectual disabilities and additional mental health problems* (O-79)
  3. R. Dalemans (S. Stans) *Being there: Social Participation through the eyes of People with Aphasia* (O-80)

  **Oxford**

- **Workshop: Experiential Knowledge**
  Moderator: J. Kool
  1. N. Lievyns *Nothing about us without us! How to fulfill participation* (O-61)
  2. J. Kool *Experiential knowledge within disability (studies) research* (O-62)

  **Erasmus 2**

- **Stream Friendship**
  **Symposium: Reciprocity and Friendship I**
  Moderator: G. van Hove
  1. D. Milton *"Welcome to the machines": autism and the acquisition of tacit knowledge* (O-51)
  2. F. Renders *Givers and receivers: auto-ethnographic stories and self-reflections about life in a Flemish institution for people with an intellectual disability* (O-52)
  3. E. Nathan *Unfolding the Proposed World We Can Inhabit Together: 'Belonging' in Art and Theology* (O-53)

  **Sorbonne**

- **Stream Inclusive Education**
  **Symposium: Belonging through Education II**
  Moderator: W. van Brakel
  1. S. Claus *"I just want them to see me as Lisa, not as the one with a disability!" How students with a disability try to find their way in a Faculty of Medicine & Health Sciences* (O-69)
  2. I. Bramsen *Educating health care students to listen to the insider perspective of people with disabilities* (O-70)
  3. P. op 't Hof *From text to texture. Count me in, a curriculum for educating the excluded* (O-71)

  **Stellenbosch**

**11:00-11:30** **Coffee & Tea Break**
**Foyer Erasmus**

**11:30-12:45** **Concurrent Sessions V**

- **Stream Social Inclusion & Representation**
  **Symposium: Making Inclusion Work**
  Moderator: M. Cardol
  1. C. Platenkamp *The art of belonging: about initiatives, limits and possibilities of belonging of disabled people: two messages* (O-13)
  2. F. Bannink *Mobility, incontinence, and social functioning of children with spina bifida in Uganda* (O-14)
  3. A. Bolsenbroek *Inclusion and Self-determination* (O-15)

  **UvA 1**

- **Stream Public Policy & Rights**
  **Symposium: The Rights of Belonging**
  Moderator: E. Luytzen de Vos
  1. Y. Cantin *French Deafs during the 1900's period : a fight for equality* (O-75)
  2. P. Björne *Self-determination and participation – implementing qualitative aspects of Swedish legislation on disability* (O-76)
  3. A. van Wijnen *Large Scale Listening: Monitoring the implementation of the UN CRPD in the Netherlands* (O-77)

  **Erasmus 1**

- **Stream Participation**
  **Symposium: Belonging: Identity & Empowerment**
  Moderator: G. van Hove
  1. T. Meulenkamp *The relation between loneliness and social participation of people with moderate or severe physical disability* (O-81)
  2. J. Holla *Peer support as a tool for belonging* (O-82)
  3. S. Kef *"Yes, I can!" The art of social participation of young adults with visual impairments* (O-83)

  **Oxford**

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

  **Erasmus 2**

- **Stream Friendship**
  **Symposium: Reciprocity & Friendship II**
  Moderator: W. van Brakel
  1. S. Sergeant *The use of images in supporting dialogue* (O-54)
  2. N. Grove *Belonging through Storysharing®: processes of attunement and reciprocity* (O-55)
  3. A. van der Putten *To enable belonging: personal relationships between persons with profound intellectual and multiple disabilities in residential facilities* (O-56)

  **Sorbonne**

- **Workshop: Accessible Society II**
  Chair: T. Visser
  G. Dingler *Dialogue workshop "The Art of Belonging"* (O-65)
  **Stellenbosch**

**12:45-13:30 Closing Ceremony**

- **Presentation *New Chair Disability Studies***
- ***Entre act: Art Loca***
- **Jetta Klijnsma, State Secretary for Social Affairs and Employment**

**Main Lecture Room**

**13:30-14:15 Lunch & Farewell**
**Foyer Erasmus, Vide & Bar upstairs**

Disability Studies International Conference 2013
'The Art of Belonging'
October 31 - November 2, 2013

## PROGRAMME (Oral & Poster)

*Streams*

- *Social Inclusion & Representation*
- *(Family) Quality of Life*
- *Empowerment & Environment*
- *Inclusive Employment*
- *Friendship*

*Streams (continued)*

- *Inclusive Methods*
- *Workshops*
- *Inclusive Education*
- *Public Policy & Rights*
- *Participation*

### Friday November 1, 2013 *11.45-12.15 h.*

**Poster Programme**

Vide/ Balcony

| | | | | | |
|---|---|---|---|---|---|
| P-1<br>*Community perspectives on increasing social participation of persons with visual impairments*<br>S. Kef | P-2<br>*Family Needs in Spain*<br>N. Baqués | P-3<br>*Disabling barriers, restrictive contextual factors for people with disabilities*<br>T. Nijhoff | P-4<br>*Self-Advocates' Evaluation of the UN Convention on the Rights of Persons with Disabilities (2006) Implementation*<br>D. Bratkovic | P-6<br>*Inclusive architectural design. Involving impaired people in the design process*<br>M. van den Wildenberg | P-7<br>*Every child belongs in inclusive education. Together with parents and children in search of inclusive learning environments*<br>M. Nossin |
| P-8<br>*Disability experience in postsocialist context: social participation as a concept and as a tool*<br>K. Pancocha | | | P-5<br>*The art of belonging and social space – How does the Convention on the Rights of Persons with Disabilities challenge society and service provision?*<br>S. Reker | | |

| Time | Thursday October 31, 2013 | |
|---|---|---|
| 12:30 | Registration Disability Studies International Conference 2013<br>'The Art of Belonging'<br>12.30 - 19.30 h. | |
| | UvA 1 | UvA 2 |
| 14:00 | **Pre-Conference Workshop I**<br>**IASSIDD Academy**<br><br>Dementia and Age-Related Decline in People with Lifelong Disabilities<br><br>M. Janicki & R. Lucchino | **Pre-Conference Workshop II**<br>**IASSIDD Academy**<br><br>Quality of Life Applications in Education & Families: Challenges and Solutions<br><br>R. Faragher & N. Zuna |
| 17:00 | Registration | |
| 18:15 | Foyer Erasmus | |
| 18:30 | Coffee & Tea break | |
| | Main Lecture Room | |
| 19:00 | Opening Conference<br>*Mother and Son Duets*<br>Music by Andrea van Beek | |
| 20:00 | Keynote<br>*Two Roads Diverged: Choreographing a Sense of Belonging for All*<br>Ann Turnbull | |
| | Erasmus 1 & 2 | |
| 21:00 | Reception | |
| 21:30 | | |

| Time | Friday November 1, 2013 - Morning | | | | | |
|---|---|---|---|---|---|---|
| 8:30 | Registration 8.30 - 17.30 h. | | | | | |
| 9.00 | | | | | | |
| | Main Lecture Room | | | | | |
| 9:15 | Keynote<br>*Sibling's Relationships and the Art of Belonging: personal experience and ethics of recognition*<br>Beatriz Miranda Galarza | | | | | |
| | Foyer Erasmus | | | | | |
| 10:00 | Coffee & Tea break | | | | | |
| 10:15 | | | | | | |
| | **Belonging: Strengths & Barriers I**<br>Moderator: G. van Hove | **Family Quality of Life**<br>Moderator: A. Schippers | **Belonging through Performance**<br>Moderator: M. Bakker | **Participation through Paid Work**<br>Moderator: W. van Brakel | **Reciprocity & Intimacy**<br>Moderator: M. Cardol | **Designing Methods for All**<br>Moderator: T. Abma |
| | UvA 1 | ERASMUS 1 | MAIN LECTURE ROOM | STELLENBOSCH | SORBONNE | ERASMUS 2 |
| 10:30 | O-01<br>*Persons with ID, poverty and inclusion. A Dutch Perspective*<br>H. Kröber | O-16<br>*Family Quality of Life: International Comparisons of 18 Studies in 14 Countries*<br>I. Brown (D. Roth) | O-24<br>*Vulnerability and the disabled body. Getting a sense of belonging through the other*<br>Y. Kelders | O-33<br>*Can't do it on their own; The work participation of young disabled persons in the Netherlands*<br>K. van Brakel | O-42<br>*The possibility of cultivating reciprocal relationships*<br>M. Hermsen | O-57<br>*One for all, all for one – working together for optimal participation of people with intellectual disabilities/Down syndrome. A connection between disability studies and patients participation perspective*<br>S. Woelders |
| 10:45 | O-02<br>*Art of Portraiture*<br>E. de Schauwer | O-17<br>*Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families*<br>L. van Heumen | O-25<br>*Technical aids, aesthetics and the mediation of belonging*<br>H. van der Horst | O-34<br>*High prevalence of early onset mental disorders among long-term disability claimants*<br>B. Cornelius | O-43<br>*The applicability of motivational interviewing among people with mild to borderline intellectual disability; a self-determination theory perspective*<br>N. Frielink | O-58<br>*Individual support planning: perceptions and expectations of people with intellectual disabilities in the Netherlands*<br>M. Herps |
| 11:00 | O-03<br>*Community-based social inclusion of citizens with mental disability and citizens with psychiatric problems; a case study at three different districts in Nijmegen*<br>A. Brummel | (continued L. van Heumen et al) | O-26<br>*Agency in the 21st century: the emperor's new clothes*<br>S. Hilberink | O-35<br>*Employment, Social Capital and Community Participation among Israelis with Disabilities*<br>T. Araten-Bergman | O-44<br>*Development of an evidence based training focused on sexuality and sexual abuse of people with intellectual disabilities*<br>K. van den Bogaard | O-59<br>*A self-advocate's right to belong as a form of resistance in higher education and disability studies*<br>T. Maillard |
| 11:15 | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | Questions and Discussion |
| 11:30 | | | | | | |
| | Vide/ Balcony | | | | | |
| 11:45 | Poster session (see Poster Programme) | | | | | |
| 12:00 | | | | | | |
| | Foyer Erasmus, Vide & Bar upstairs | | | | | |
| 12:15 | Lunch | | | | | |
| 12:30 | | | | | | |
| 12:45 | | | | | | |
| 13:00 | | | | | | |

# Friday November 1, 2013 - Afternoon

| Time | | | | | | |
|---|---|---|---|---|---|---|
| | **Belonging: Strengths & Barriers II**<br>Moderator: M. Cardol | **Family & Disability Issues**<br>Moderator: A. Schippers | **Adapting the Environment I**<br>Moderator: J. Kool | **The Essentials of Belonging: Inclusive Employment**<br>Moderator: K. Vornholt | **Hybrid Spaces of Belonging**<br>Moderator: G. Widdershoven | **Workshop: Accessible Society I**<br>Moderator: T. Visser |
| | UvA 1 | ERASMUS 1 | MAIN LECTURE ROOM | STELLENBOSCH | SORBONNE | ERASMUS 2 |
| 13:15 | O-04<br>*Precarious Belonging: Chronic Homelessness and People with Impaired Decision Making Capacity*<br>J. Clapton | O-18<br>*Understanding Disability Belief Systems: Family Perspectives and Impact*<br>N. Zuna | O-27<br>*Avatar: Ableism and Normalization*<br>S. Flynn | O-36<br>*Experiences with the Method 'Inclusive Redesign of Work Processes'*<br>G. van Ruitenbeek | O-45<br>*Social media and people with intellectual disabilities*<br>C. Shpigelman | O-60<br>*The Power of Valued Social Roles*<br>H. Kroon |
| 13:30 | O-05<br>*Sharing Limburg – Including people with dementia in a process of cultural reproduction*<br>R. Hendriks | O-19<br>*Working with parents of children with a disability – a continuing dialogue*<br>E. de Schauwer | O-28<br>*How to turn technical aids into social mediators?*<br>M. Hoogsteyns | O-37<br>*Acceptance of People with Disabilities at Work. A literature review and validation of a newly developed questionnaire*<br>K. Vornholt | O-46<br>*Inclusion as Heterotopia: Spaces of Encounter Between People With and Without Intellectual Disability*<br>H. Meininger | |
| 13:45 | O-06<br>*Autism and the art of communication*<br>M. Pater | O-20<br>*Parents' concerns about their child's doing, being, becoming and belonging*<br>B. Piškur | O-29<br>*Creating a positive view*<br>P. van der Kaa | O-38<br>*The Building Blocks of an Inclusive Climate*<br>P. Nelissen | O-47<br>*"Focus on Friendship"; (dialogue) conversations about social relations with secondary schools and their students with autism*<br>G. Dingler | |
| 14:00 | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | |
| 14:15 | | | | | | |
| | Main Lecture Room | | | | | |
| 14:30 | Short Film - Art Loca | | | | | |
| 14:45 | *Video presentation Hans Reinders: What makes Belonging an Art?* | | | | | |
| | Foyer Erasmus | | | | | |
| 15:00 | Coffee & Tea break | | | | | |
| 15:15 | | | | | | |
| | **Representation**<br>Moderator: J. Kool | **Belonging & Quality of Life**<br>Moderator: N. Zuna | **Adapting the Environment II**<br>Moderator: G. van Hove | **Work as Catalyst for Belonging**<br>Moderator: W. van Brakel | **Belonging 'Inside-Out'**<br>Moderator: H. Meininger | **Belonging through Education I**<br>Moderator: B. Miranda Galarza |
| | UvA 1 | ERASMUS 1 | MAIN LECTURE ROOM | STELLENBOSCH | SORBONNE | ERASMUS 2 |
| 15:30 | O-07<br>*When "awareness" becomes stigma: Representations of autism in charity campaigns and the media, and their impact on people with autism*<br>M. Waltz | O-21<br>*Family support and public policy*<br>R. Turnbull | O-30<br>*The User-Initiated Design Phenomenon in Stroke Survivors: Adapting Inaccessible Environments*<br>M. Sarmiento | O-39<br>*Autism Spectrum Disorders and Intellectual Disabilities: Private-Sector Workplace Discrimination in the U.S.A.*<br>T. van Wieren | O-48<br>*Friendships: a personal story of formation, loss and maintenance*<br>J. McDonagh | O-66<br>*Looking through a new lens: educational status quo and the social model of disability*<br>A. Sakellariadis |
| 15:45 | O-08<br>*Who Makes the Portrait? Whose Portrait is it? Portraiture as Interplay between Participant, Portraitist and Audience*<br>K. de Munck | O-22<br>*The application of the oriental dance to persons with intellectual disabilities*<br>A. Žic Ralić | O-31<br>*Culture for Everybody? Museums and Galleries Accessible for Deaf Pupils in the Czech Republic, France and Sweden*<br>M. Koutská | O-40<br>*Active inclusion of young people with health problems or disabilities in 11 EU-Member States*<br>E. de Vos | O-49<br>*Hear, look, touch. Stories about self-transforming experiences in proximity of, and encounters with other bodies*<br>G. Bos | O-67<br>*Preschool children's attitude-perception towards children with disability*<br>D. Roth |
| 16:00 | O-09<br>*"Does my daughter really belong in our society?"*<br>S. Banens | O-23<br>*What can positive psychology contribute to enhancing the quality of life of persons with (intellectual) disabilities?*<br>W. Buntinx | O-32<br>*Accessibility for people with different kinds of disabilities in community organizations in Amsterdam*<br>S. van Zal | O-41<br>*Key elements in transition from school (VSO) to employment: a survey and a new approach*<br>C. Aarnoutse | O-50<br>*Towards a prototypical conceptual model for the interrelations among disability, belonging and leisure*<br>J. Bouwer | O-68<br>*Can disabled children in the Netherlands get access to (mainstream) education by litigation in international courts and in this way to the status of belonging?*<br>T. Grooff |
| 16:15 | *Questions and Discussion* | Questions and Discussion | Questions and Discussion | Questions and Discussion | Questions and Discussion | *Questions and Discussion* |
| 16:30 | | | | | | |
| 16:45 | Main Lecture Room | | | | | |
| 17:00 | Keynote<br>*Disability and the Creative Art of Belonging*<br>Simi Linton | | | | | |
| | | | | | | |
| 17:45 | | | | | | |
| 18:00 | | | | | | |
| 18:15 | | | | | | |
| | Bar upstairs | | | | | |
| 18:30 | Conference Dinner | | | | | |
| 18:45 | | | | | | |
| 19:00 | | | | | | |
| 19:15 | | | | | | |
| 19:30 | | | | | | |
| 19:45 | | | | | | |
| 20:00 | | | | | | |
| 20:15 | | | | | | |

| Time | Saturday November 2, 2013 | | | | | |
|---|---|---|---|---|---|---|
| 8:30 | Registration 8.30 - 14.00 h. | | | | | |
| 8:45 | | | | | | |
| | Main Lecture Room | | | | | |
| 9:00 | Keynote | | | | | |
| 9:15 | *Reflection 2nd Disability Studies International Conference 2013* | | | | | |
| 9:30 | Robert Maier | | | | | |
| | **Inclusive Relations**<br>Moderator: M. Bakker | **Social Network & Public Policy**<br>Moderator: B. Miranda Galarza | **Participation: Belonging Together**<br>Moderator: M. Cardol | **Workshop: Experiental Knowledge**<br>Moderator: J. Kool | **Reciprocity & Friendship I**<br>G. van Hove | **Belonging through Education II**<br>Moderator: W. van Brakel |
| | UvA 1 | ERASMUS 1 | OXFORD | ERASMUS 2 | SORBONNE | STELLENBOSCH |
| 9:45 | O-10<br>*Transitions: a journey through child-based health services to adult services - a personal account*<br>J. McDonagh | O-72<br>*Financial incentives for independent living*<br>H. van Haaster | O-78<br>*Participation in terms of belonging to this AND that*<br>M. Cardol | O-61<br>*Nothing about us without us! How to fulfill participation*<br>N. Lievyns | O-51<br>*"Welcome to the machines": autism and the acquisition of tacit knowledge*<br>D. Milton | O-69<br>*"I just want them to see me as Lisa, not as the one with a disability!" How students with a disability try to find their way in a Faculty of Medicine & Health Sciences*<br>S. Claus |
| 10:00 | O-11<br>*iSupporter*<br>M. Nossin | O-73<br>*Needs and Challenges of Care Givers of Adolescents with Developmental Disabilities in Georgia*<br>T. Makaradze | O-79<br>*"Longing to belong". Spaces of (non-) belonging in the life trajectories of people with intellectual disabilities and additional mental health problems*<br>L. Claes | O-62<br>*Experiential knowledge within disability (studies) research*<br>J. Kool | O-52<br>*Givers and receivers: auto-ethnographic stories and self-reflections about life in a Flemish institution for people with an intellectual disability*<br>F. Renders | O-70<br>*Educating health care students to listen to the insider perspective of people with disabilities*<br>I. Bramsen |
| 10:15 | O-12<br>*"Andreas is a child in MY class!" Developing a support concept for teachers while working with diverse students*<br>I. van de Putte | O-74<br>*Historicizing the art of belonging. Disability, activism and social science in the United Kingdom and the Netherlands since the 1960s*<br>P. van Trigt | O-80<br>*Being there: Social Participation through the eyes of People with Aphasia*<br>R. Dalemans (S. Stans) | | O-53<br>*Unfolding the Proposed World We Can Inhabit Together: 'Belonging' in Art and Theology*<br>E. Nathan | O-71<br>*From text to texture. Count me in, a curriculum for educating the excluded*<br>P. op 't Hof |
| 10:30 | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | | *Questions and Discussion* | *Questions and Discussion* |
| 10:45 | | | | | | |
| | Foyer Erasmus | | | | | |
| 11:00 | Coffee & Tea break | | | | | |
| 11:15 | | | | | | |
| | **Making Inclusion Work**<br>Moderator: M.Cardol | **The Rights of Belonging**<br>Moderator: E. Luytzen de Vos | **Belonging: Identity & Empowerment**<br>Moderator: B. Miranda Galarza | **Workshop: Belonging in Education**<br>Moderator: J Jansen | **Reciprocity & Friendship II**<br>Moderator: W. van Brakel | **Workshop: Accessible Society II**<br>Moderator: T. Visser |
| | UvA 1 | ERASMUS 1 | OXFORD | ERASMUS 2 | SORBONNE | STELLENBOSCH |
| 11:30 | O-13<br>*The art of belonging: about initiatives, limits and possibilities of belonging of disabled people: two messages*<br>C. Platenkamp | O-75<br>*French Deafs during the 1900's period : a fight for equality*<br>Y. Cantin | O-81<br>*The relation between loneliness and social participation of people with moderate or severe physical disability*<br>T. Meulenkamp | O-63<br>*Universal Design for Learning: belonging to education*<br>J. Jansen | O-54<br>*The use of images in supporting dialogue*<br>S. Sergeant | O-65<br>*Dialogue workshop "The Art of Belonging"*<br>G. Dingler |
| 11:45 | O-14<br>*Mobility, incontinence, and social functioning of children with spina bifida in Uganda*<br>F. Bannink | O-76<br>*Self-determination and participation – implementing qualitative aspects of Swedish legislation on disability*<br>P. Björne | O-82<br>*Peer support as a tool for belonging*<br>J. Holla | O-64<br>*Universal Design for Learning: How can we make it everybody's business?*<br>K. de Munck | O-55<br>*Belonging through Storysharing®: processes of attunement and reciprocity*<br>N. Grove | |
| 12:00 | O-15<br>*Inclusion and Self-determination*<br>A. Bolsenbroek | O-77<br>*Large Scale Listening: Monitoring the implementation of the UN CRPD in the Netherlands*<br>A.van Wijnen | O-83<br>*"Yes, I can!" The art of social participation of young adults with visual impairments*<br>S. Kef | | O-56<br>*To enable belonging: personal relationships between persons with profound intellectual and multiple disabilities in residential facilities*<br>A. van der Putten | |
| 12:15 | *Questions and Discussion* | *Questions and Discussion* | *Questions and Discussion* | | *Questions and Discussion* | |
| 12:30 | | | | | | |
| | Main Lecture Room | | | | | |
| 12:45 | Presentation new chair Disability Studies | | | | | |
| 13:00 | *Entre act: Art Loca* | | | | | |
| | Jetta Klijnsma | | | | | |
| 13:15 | State Secretary for Social Affairs and Employment | | | | | |
| | Foyer Erasmus, Vide & Bar upstairs | | | | | |
| 13:30 | Lunch and Farewell | | | | | |
| 13:45 | | | | | | |
| 14:00 | | | | | | |
| 14:15 | | | | | | |

# Preconference parallel workshops

*Thursday October 31, 2013*
14:00 – 17:00 h.

Two workshops will be offered prior to the conference that will share recent scientific knowledge in specific areas of disability and highlight how such knowledge can be used in policy and practice. These workshops appeal to professionals working in disability services, health care, and education. Workshop leaders are internationally acclaimed scholars in their particular area of disability, and are sponsored by the Academy for Teaching, Learning and Research, a branch of the International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD).

## Workshop 1

**Topic: Dementia and Age-Related Decline in People with Lifelong Disabilities**

**Workshop Leaders**
1. Matthew P. Janicki, Ph.D.
University of Illinois at Chicago and Co-Chair of the US National Task Group on Intellectual Disabilities and Dementia Practices
2. Ronald Lucchino, Ph.D.
Utica College (Utica, New York) and Area Agency on Aging of Southwest Florida

As providers are seeing the general age of their clientele markedly increase, concerns are growing about how to plan for and address age-associated pathologies. One such age-associated condition, Alzheimer's disease and related dementias, affects a significant number of adults with lifelong disability. Many at-risk adults live on their own or with friends, and many affected adults live in small community group homes or with their families. How to provide sound and responsive community care is a growing service challenge. This session provides an overview of key elements of dementia in adults with lifelong disabilities and examines strategies agencies can employ to adapt their current services to make them 'dementia capable' and well as address pharmaceutical and nonpharmaceutical interventions. Specifically covered are the elements of dementia, as well its onset, duration and effect, and techniques for adapting environments and programs. Models for supports depending on the stage of dementia are also discussed, as are training foci areas and community care models that provide for "dementia capable" supports and services. Covered also awareness of adverse drug reactions and how these may mimic dementia and affect cognitive decline.

## Workshop 2

**Topic: Quality of Life Applications in Education & Families: Challenges and Solutions**

**Workshop Leaders**
1. Rhonda Faragher Ph.D., Head of School and Senior Lecturer
Faculty of Education, Canberra Campus Australian Catholic University
2. Nina Zuna, Meredith Brinster
The Meadows Center for Preventing Educational Risk, The University of Texas at Austin, Department of Special Education, Austin, USA

*Three short lectures plus group discussion.*
*1) Quality of life approaches and models from Intellectual and Developmental disabilities*
Recently there has been discussion about the applicability of quality of life and family quality of life approaches and principles for all individuals and families who face challenges. This presentation, using examples based on an upcoming book, discusses the possibilities and challenges at levels of research, policy and practice.
*2) The Application of Quality of Life Principles in Education*
Discussion regarding quality of life and education in schools and universities is an area which has largely been unexplored as a field of serious study and application. In this presentation the need for the implementation of such an approach is discussed along with practical examples of how it may be applied.
*3) Family Quality of Life: Understanding the family life experience*
Successful children live in supportive, healthy family environments. In this workshop, we examine what family members in 18 studies carried out in 14 countries say about their family quality of life, and we discuss how this helps us in supporting families.

# Keynote lectures

## Two Roads Diverged: Choreographing a Sense of Belonging for All

Prof. Dr. Ann Turnbull
Beach Center on Disability, The University of Kansas, Lawrence, USA

**Theme**
Ann Turnbull will blend theory, research, and her own family experiences as the mother of a son with significant multiple disabilities. She will describe a process for supporting individuals with intensive support needs to experience authentic belonging through actualizing great expectations, building on their strengths, experiencing self-determination, and being full citizens of their communities. She will incorporate video clips to provide examples of what it means to truly belong.

**Biography**
Dr. Ann Turnbull has been a professor, researcher, and advocate for individuals with disabilities, their families, and service providers for four decades. She has authored 32 books and over 250 articles and chapters. In 1999, she was selected as one of 36 individuals who have "changed the course of history for individuals with intellectual and developmental disabilities in the 20th century." In 1990, she received the "International Leadership Award" from the Joseph P. Kennedy, Jr. Foundation. Her greatest learning has come from her son, Jay Turnbull, who she has always called her "best professor" about the needs of individuals with significant disabilities over the lifespan. Given Ann's family role, she seeks to be a bridge between the "daily reality" of the disability world and the academic/scientific world.

## Video presentation: What Makes Belonging an Art?

Prof. Dr. Hans Reinders
Faculty of Theology, VU University Amsterdam, the Netherlands

**Theme**
Belonging as an art means that people have learned to use the skills they have developed in one area of their lives also in other area's, thereby expanding their range of activities from their own strength.

A video presentation by Hans Reinders, Professor of Ethics at VU University Amsterdam
Video production: Huub Rutjes and Jasper Reinders.

**Biography**
Professor Hans Reinders has been working in the field of intellectual disability for more than 20 years, and has published widely on a variety of topics concerning the lives of people with disabilities and their families. He is professor of ethics at VU University Amsterdam, where he also holds the Bernard Lievegoed Chair of ethics and disability. He is the general editor of the *Journal of Religion, Disability & Health*, and chairs the *European Society for the Study of Theology and Disability*. He is currently involved in research concerning Quality of Life as the key concept in assessing the quality of human services.

Foto: StudioVU/Yvonne Compier

## Disability and the Creative Art of Belonging

Simi Linton
Disability/Arts Consultancy, New York City, USA

Her presentation will be a combination of a keynote and a cultural programme.

**Theme**

In recent years, disabled people have emerged from our various closets, challenging society's limited vision of community and citizenship. In the midst of this, a robust disability arts movement has grown to shape a new image of disability in the public imagination. This presentation explores this social and cultural landscape, and our role in a more inclusive and equitable society.

**Biography**

Simi Linton, Ph.D. is the author of *Claiming Disability: Knowledge and Identity*, the memoir *My Body Politic*, and numerous articles on disability. Linton was on the faculty of the City University of New York for 14 years, leaving in 1998 to write, and develop her consultancy work. She has worked with filmmakers, artists and cultural institutions (such as The Smithsonian, The Margaret Mead Film Festival and The Public Theater) to shape the presentation of disability in the arts and to increase the representation of works by disabled artists. Linton holds an undergraduate degree in psychology from Columbia University, and a Ph.D. from New York University. She is currently Co-Producer/Director of the forthcoming documentary film, *Invitation to Dance*.

## Sibling's relationships and the art of belonging: personal experience and ethics of recognition

Beatriz Miranda Galarza
PhD, Athena Institute, VU University, 17 Institute of Critical Theory

**Theme**

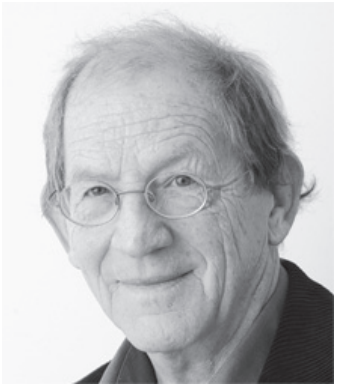
Literature about the psychological impact of having a disabled member in a family has overwhelmed the field of family and disability. Furthermore, little has been written about siblings of disabled people and especially of people labelled as intellectually disabled and their world-making considering interaction, space and time all linked to disability. In this presentation I would like to address the topic of ethics of recognition regarding siblings relationships and disability. I will draw on ideas of intimacy, decolonising approaches and recovering the value of personal experience in order to understand the art of belonging and siblinghood.

**Biography**

Beatriz Miranda Galarza is postdoc researcher at the Athena Institute, VU University Amsterdam. She also collaborates with the 17 Institute of Critical Theory in Mexico regarding Disability Critical Studies. She is from Ecuador.
Education: PhD Sociology and Disability Studies, Leeds University, UK; MA Anthropology, KU Leuven, Belgium; MSc. Social Development, IT Monterrey, Mexico; MA Latin American Studies, UASB- Quito, Ecuador; BSc. Sociology and Political Sciences, Central University, Ecuador.
Experience: Her main field of study and research has been development and disability. She has been involved in social research and cooperation projects in the USA, Central and South America, Belgium, England, India, China and Indonesia looking at social issues linked to AIDS, disability, gender, religion, street children, post-coloniality, race and ethnicity. At the present, she is the study manager of the SARI Project in Indonesia that aims to understand the life of people affected by leprosy in West-Java towards an improvement of their life conditions. She teaches Disability research, Sociological approaches to stigma and Sociology of the body at the Athena Institute, VU University of Amsterdam and Medical Anthropology at the Amsterdam University College AUC.

## Reflection 2nd International Disability Studies Conference 2013

Prof. dr. Robert Maier
Professor emeritus at Social Faculty of Utrecht University, scientific advisor of Disability Studies in the Netherlands



**Theme**

'The art of belonging' as title of the congres of Disability Studies asks to be questioned. This contribution will provide a critical reflection on the following points: firstly, the question is asked whether the conditions facilitating belonging are taken into account; secondly, the inherent complexity of the concept of belonging will be discussed, and finally, this reflection will examine the relation between belonging on the one hand, and the community to which one belongs on the other hand.

**Biography**

Robert Maier is professor emeritus of Utrecht University, where he is still attached to the research program 'Work, Care and Solidarity'. Moreover, he is teaching a class at the university for the third age. He was involved in several comparative European research programs on work, integration and marginality. He has authored some ten books, and a great number of articles and chapters in books. Sinds 2010 he is scientific advisor of Disability Studies in the Netherlands; and he is research fellow of the Konrad Lorenz Institute at Vienna.

## It's all about belonging: trying to find a useful balance between 'activism' and 'science'

Prof.dr. Geert Van Hove
Ghent University, Belgium – Disability Studies in the Netherlands

**Theme**

In the Netherlands Disability Studies has a strong connection with the ngo DSiN. This tight link opens a window of opportunities to combine the quest for:

- A strong theoretical-conceptual framework
  With
- The wealth of personal experiences and perspectives
  And
- A solid program for scientific research.

The ultimate goals of DSiN are clear and in accordance with the general principles of the UN Convention on the Rights of Persons with Disabilities (respect, non-discrimination, full and effective participation, persons with disabilities as part of human diversity, equality of opportunities, accessibility, equality between men and women, respect for the evolving capacities of children with disabilities)

While building a scientific DS project in the Netherlands DSiN and the Free University of Amsterdam will not flee from the confrontation with e.g.:

- Tensions between old and new paradigms of care and support
- The impact of certain general attitudes living in the community towards persons with disabilities
- Neo-liberal tendencies that replace 'interdependence' and 'relational citizenship' with 'pure self-reliance' and the principles of the 'survival of the fittest'
- The effects of globalization on local situations of care/support and human rights.

**Biography**

Before working at Ghent University Geert Van Hove founded one of the first projects of supported living for persons with intellectual disabilities in Belgium.

Since 1993 he works as a University Professor in close collaboration with colleagues-researchers, families of children with disabilities who have chosen to bring their children to regular schools and the self-advocacy movement Our New Future. Within the above described projects and themes a group of Disability Studies oriented researchers has tried to learn within a balance between activism and science.

# Abstracts poster presentations

## P - 1

**Community perspectives on increasing social participation of persons with visual impairments**
Sabina Kef, Karen Sleurink
VU University Amsterdam, Faculty of Psychology and Education, Clinical Child and Family Studies, Amsterdam, the Netherlands

**Aim**
Hopes of successful participation of young people with Visual Impairments (VI) are often dampened by difficulties they encounter in society. In order to improve chances for participation, this study explores community perspectives on VI in general and common attitudes towards the chances for social participation of individuals with VI in the Netherlands. Furthermore, we are interested in differences between subgroups in our society.

**Methods**
Data of a national longitudinal study on young adults with VI (N=300) were used to examine their feelings of stigmatization. Community perspectives on visual impairment and attitudes towards social participation of young persons with VI were measured with closed and open ended questionnaires. Data are being collected this spring in schools, university campus and public places.

**Results**
Results are not complete yet, because data from the second wave have to be compared with our current study on community perspectives and attitudes. Data from the second wave showed gender differences in perceived stigmatization of young persons with VI. Furthermore, they experienced participation problems, which were negatively related to psychosocial characteristics like self-esteem, acceptance of impairment and loneliness. Data will be presented on community perspectives on participation of persons with VI, to be able to compare them with perceived feelings of stigmatization.

**Conclusions**
Data from the second wave suggested differences in *perceived* and *actual* stigmatization. The results of this current study can be used to clarify this issue and to refine environmental interventions to promote social participation and acceptation of impairments in society. This is especially relevant given the transition of types of care/support to local authorities.

## P - 2

**Family Needs in Spain**
Natasha Baqués[1], Climent Giné[1], Rosa Vilaseca[2], Marta Gràcia[2], Anna Balcells-Balcells[1], Joana M. Mas[1]
[1] Ramon Llull University, Barcelona, Spain
[2] University of Barcelona, Barcelona, Spain

**Aim**
The Family Needs Assessment scale (FNA) is an international project shared by different countries and lead by Dr. A. Turnbull, Kansas University (USA). The aim of our study is to present the results of the normalization and standardization process of the FNA carried out with families with a member with intellectual disabilities (ID) up to 18 years old in Catalonia. The goals of the scale are: (a) to assess the family support needs of families with a member with ID, (b) to know the most relevant needs of the families and (c) to identify the supports that would match their family needs.

**Methods**
In order to obtain a valid and reliable scale that identifies the Catalan families' support needs, the process followed has been: (a) to develop jointly with the other countries involved in the project the scale and the item pool and to adapt the scale to Spanish and Catalan languages; (b) the expert assessment; (c) the pilot study; and (d) the normalization and standardization procedure. Furthermore the impact of family needs in the family quality of life perceptions has been analyzed.

**Results**
The social-demographic data, the psychometric properties of the scale, the perception of Catalan families about their support needs and the relationship between families' support needs and the family quality of life will be presented.

**Conclusion**
Implications of the scale use and the next steps of the study will be discussed.

## P – 3

**Disabling barriers, restrictive contextual factors for people with disabilities**
Taco A. Nijhoff, Rina Nijkamp, Monique Groeneweg and students
Minor disability studies (in Dutch), University of applied sciences Utrecht, Utrecht, the Netherlands

**Aim**
In the minor disability studies (DS) students from different courses and disciplines learn what it is to live with an impairment in today's society. The goal is that they learn to work together with disabled people (meeting and collaboration) and learn how to create new opportunities for support to ultimately improve quality of life of disabled people and to make active participation in society possible for everyone. Hindering contextual factors for participation (disabling barriers) were examined in all areas of life (e.g. labor, politics, education, leisure, social services and networks).

**Methods**
In the minor DS students immersed themselves into the lives of people with disabilities by reading experience stories and doing experience assignments. Subsequently students investigated different environmental factors according to the International Classification of Functioning, Disability and Health (products and technology; natural environment and human-made changes to environment; support and relationships; attitudes; services, systems and policies). The research method depended on the chosen topic. Thereafter they were holding interviews with disabled people to investigate the influence of an environmental factor on participation of people with disabilities. Results were described in portfolios.

**Results**
In a wheelchair students experienced many physical barriers in accessibility of public buildings, transport and public services. The adaptive task was to perform all the usual daily activities but no one succeeded to do all. Students were surprised by the variable reactions from unknown bystanders. Difficulties or impossibilities for participation for disabled was found in mobility, public space, cinema's , fitness centers, shops, public transportation, toilet facilities, museums, restaurants and housing facilities due to inaccessibility and lack of information or support.
Interviews revealed that people with different and comparable disabilities share similar experiences like incomprehension of others, dependence on support but they can demonstrate different coping styles and mixed emotions.

**Conclusions**
Disability is an adaptive challenge which comes along with many emotions. Processes of exclusion, forms of support and adaptation to the constraints will be discussed.

## P – 4

**Self-Advocates' Evaluation of the UN Convention on the Rights of Persons with Disabilities (2006) Implementation**
Daniela Bratkovic[1], Tereza Glucina[2] and Snjezana Kanjir[3]
[1] Faculty of Education and Rehabilitation Sciences, University of Zagreb, Zagreb, Croatia
[2] Association for Self-Advocacy, Zagreb, Croatia
[3] Association for Self-Advocacy, Zagreb, Croatia

**Aim**
The aim of this study was the assessment of the implementation of the UN Convention on the Rights of Persons with Disabilities (2006) in Croatian laws and practice by people with intellectual disability.

**Methods**
The inclusive research with members of the Croatian Association for the Self-Advocacy has been conducted. Self-advocates participated in all stages of research as equal partners. They were particularly interested in analysing the realization of the rights of people with intellectual disability in Croatia guaranteed with articles 9, 12, 18, 19, 21, 23 and 27 of the Convention. For that purpose a semi-structured interview was created and applied with 12 research participants. Data were obtained and analyzed through qualitative method.

**Results**
Although Croatia has in 2007 ratified UN Convention on the Rights of Persons with Disabilities, its implementation in reality, as estimated by self-advocates, is not satisfactory. According to their views and opinions, actual Croatian laws still have not been adequately aligned with proposed principles in several analyzed articles of the Convention. Therefore people with ID are still facing barriers, difficulties, and limited access to employment, legal capacity, independent living, community support, right to marriage and access to information.

**Conclusions**
This study demonstrated potentials, needs and desires of self-advocates to actively participate and influence social development and improvement of implementation the UN Convention in legal framework and practice, which significantly marked their quality of life. The sense of their identity and belonging to the community, they connect tightly with the level of realisation of equal rights and possibilities.

## P – 5

**The art of belonging and social space – How does the Convention on the Rights of Persons with Disabilities challenge society and service provision?**
Sarah Reker
Max Planck Institute for Social Law and Social Policy, Division: Inclusion and Disability, Munich, Germany

**Aim**
The Convention on the Rights of Persons with Disabilities (CRPD) provides the basis of this study. For all countries which have ratified the Convention since its entry into force in 2007, the effective implementation of the requirements often leads to considerable challenges. Furthermore, missing indicators make it difficult to measure progress. Therefore, the aim of the research project is to contribute to analyzing the consequences of the implementation process on the inclusion and exclusion conditions for people with disabilities in Germany.
Disabled People's Organisations and other associations consider the social space to be relevant for the successful implementation of the CRPD. Against this background, the research project wants to focus on the relationship between a barrier-free access to the social space and the "full and effective participation and inclusion" (Art. 3) of persons with disabilities. The theoretical basis of the study is the sociological and socio-scientific theory of social space ("Sozialraumtheorie").

**Methods**
With respect to the methodology, the study is based on a multidimensional approach including qualitative interviews and document analysis (e.g. mission statements of the organizations), which might be complemented by observations. My plan is to visit three different residential facilities for persons with disabilities and conduct about twenty interviews with members of the management, employees and residents with disabilities. By combining different methods of qualitative research, I would like to find out about the level of social space orientation in the field of services for persons with disabilities.

**Results**
The research will provide more information about how social spaces are constructed for and by people with disabilities. The evaluation process will be based on the International Classification of Functioning, Disability and Health (ICF).

**Conclusions**
As the data collection has not been completed yet, no final conclusions can be drawn so far. But I assume that a social space orientation in connection with the CRPD could contribute to a more inclusive belonging especially for people with disabilities who live in residential facilities.

**References**
Löw, Martina (2006) "The Constitution of Space. The Structuration of Spaces Through the Simultaneity of Effect and Perception". *European Journal of Women's Studies*. Vol. 11, No. 1, pp. 25-49.

## P – 6

**Inclusive architectural design. Involving impaired people in the design process**
M. van den Wildenberg[1], D. Arets[2]
[1] Stichting Bartiméus, Doorn, the Netherlands
[2] Design Academy Eindhoven, Eindhoven, the Netherlands

**Aim**
We are becoming more conscious of the impact of our surroundings on our wellbeing. The majority of architects focus on creating outstanding, eye catching buildings, whereas more awareness of impairments and minimal adaptations to the design, architecture and decoration can often lead to impressive improvements in recovery, wayfinding, or well being of the users, including impaired people.
The abundant use of glass facades and complex structures are maybe a relish for the eye, but people with all kinds of disabilities (visual impairment, deafness, physical impairment, a mental disorder or dementia), have problems with wayfinding or suffer from the acoustics climate. Also there are hardly good examples on involving, touch or smell in architectural buildings.
Bartiméus, knowledge institute for blind and visual impaired, focuses on improving the quality of life for people with impairments. By involving them in the research and design process of new built projects (housing/ schools) Bartiméus gained lots of experience on aspects the target group themselves considers important for their autonomy, their well being and wayfinding.

**Methods**
Bartimeus collect dates from diagnostic research on people with a visual impairment. Beside this empirical research, Bartiméus also uses the results of other research-fields to improve accessibility of the built environment. That includes research on architecture topics as well as ergonomics and environmental psychology[3].

**Results**
Results give information what sensory aspects (sound/acoustics, texture/ tactile elements, smell, light & colours) can improve the environment. In November 2012 this expertise was published in the book 'Architectuur door andere ogen' (*Architecture through different eyes)*[4]. In this multi-media publication, eight blind people visited public buildings and shared their experiences on audio documentaries. The second part of the book focuses on the above mentioned sensory aspects that architects and designers should take into account to create a more accessible environment for everyone, including people with a disability.

**Conclusions**
We are convinced that involving users in the design and research process is essential to create better living environments for everyone, including people with disabilities. Architecture is a human product and should therefore preferably reflect as many human qualities as possible.

**References**
[3] O.a. The center for Universal design, Schifferstein, Multi sensory design. Herssens, architecture for more, Herssens en Heylighen, Haptic design research, a blind sense of space. Den brinker en Daffertshofer, the IDED method to measure the visual accessibility of the built environment. W. Hoeven, olfactorische architectuurwaarneming.
[4] www.uitgeverijdekunst.nl

## P – 7

**Every child belongs in inclusive education. Together with parents and children in search of inclusive learning environments**

M. Nossin, Baukje E. van der Veen, Astrid Greven
Perspectief, kenniscentrum voor inclusie en zeggenschap, Utrecht, the Netherlands

**Aim**

The name of the project is IkLeerOok (it ran from Sept '10 – March '13). It has been executed by the authors and a team of facilitators for Perspectief - center for inclusion. The project was funded by the ministry of Health. By working closely with ten families and their network IkLeerOok aimed to improve the (inclusive) learning environment for *all* children.

**Methods**

IkLeerOok provides support in the form of a facilitator per family with a child with a disability, who thinks along with them. Parents, children and facilitators learn together, their relationship is built on equality and reciprocity and they all bring expertise. Children and parents manage this process. Also, their experiences are the greatest source of learning. They share among themselves and with other parents and schools all clues to bring about change.

**Results**

A summary of results:

- A young person has gained access to university
- Children gained access to primary education or could continue
- Young persons have gained access to mainstream secondary education
- Collaboration between regular and special schools
- Children have more contact with classmates after creating greater awareness among teachers about friendships
- Three schools have cooperated with IkLeerOok in research based on the Index for Inclusion
- Families experience more understanding and support from their network
- Families and schools have more knowledge about rights and inclusion

**Conclusions**

These results must not conceal an ever difficult reality. Inclusion in Dutch education is still far away. This project has uncovered specific obstacles and Perspectief, in collaboration with families, continues researching how to transform these into milestones. The support of a process facilitator is helpful to families. Its innovative role and capabilities are mapped by us and will be investigated further.

## P – 8

**Disability experience in postsocialist context: social participation as a concept and as a tool**

Karel Pancocha, Lenka Slepickova
Institute for Research on Inclusive Education, Faculty of Education, Masaryk university, Brno, Czech Republic

Participation is used worldwide in many disciplines as a theoretical concept, important for understanding involvement and inclusion in many life situations and, at the same time, key empirical indicator of inclusion used in surveys. It can be a useful tool to measure outcomes of programs focused on supporting inclusive practices in schools, workplace and other areas of social life. This paper presents the changes leading to a more inclusive society within the specific, post socialist context of the Czech Republic through the concept of participation as one way of understanding and assessing inclusion. However, we are not interested in creating a "busyness" index, but to analyze participation enfranchisement in people with disabilities. Therefore, we do not focus on the amount of participation as compared with some kind of social ideal or desirable state of the art, but look at important aspects of participation as identified by people with disabilities themselves. We analyze the experience of participation of people with various types of disabilities in their everyday life. For this purpose we adapted and administered a survey based on Community Participation Indicators (Heinemann, 2010), focusing on three areas of participation enfranchisement – Choice and Control,

Contributing to One's Community and Valued by Others. In this paper we will discus this scale as a tool for measuring social participation in various social contexts and present findings concerning the experience of people with disabilities with participation reflecting them in the context of the social world of a specific postcommunist society.

**References**

Heinemann, Allen W. 2010. Measurement of Participation in Rehabilitation Research. *Archives of Physical Medicine and rehabilitation* 91 (9): S1 – S4.

# Abstracts oral presentations

## Stream: Social Inclusion & Representation

### *Symposium:* Belonging: Strengths & Barriers I

### O – 01

**Persons with ID, poverty and inclusion**
**A Dutch Perspective**
Hans Kröber[1,2], Manon Verdonschot[3]
[1] Vilans, Utrecht, the Netherlands
[2] Inclusie.nu, Dordrecht, the Netherlands
[3] Manon Verdonschot onderzoek & advies, Herten, the Netherlands

**Aim**
This study is focused on the topic of poverty in relation to inclusion . The following research questions will be discussed. How is poverty defined? What data are available on poverty and people with disabilities? What are the causes and the effects of poverty in the field of belonging and inclusion? Also is examined how the support around 'poverty and inclusion' is organised, where the gaps are and how improvements can be achieved.

**Methods**
Chosen is for a combination of a qualitative and quantative research design. The study started with a literature scan. Known sources and the database Pubmed were consulted. Based on the literature a first conceptual model was developed. This model is used to collect and analyze data. The qualitative part of the research is based on several data collection methods (triangulation, 17 interviews; observations; memberchecks). During the coding process the codes were derived from the main features of the conceptual model.

**Results**
The descriptive results showed that poverty is a complex social problem and a concept with different dimensions. People with disabilities are at risk when it comes to poverty. Both causes in the environment ( for example complex law and regulations; habitat; wrong networks ) and factors associated with the individual ( for example a lack of skills; an addiction) are responsible. Poverty has a major impact on the different domains of quality of life of people with a disability and the enviroment. Belonging and participating in society is severely under pressure. Finding the right support is important. We found in this study examples of formal and informal support. Because of the complexity of all the regulations and the bureacracy, the supportworkers in care organisations don't know how to act.

**Conclusions**
We conclude, first, that poverty in the Netherlands is increasing and that persons with a disability are a group at risk. Poverty has a negative impact the quality of life and inclusion. When you do not have money it is hard to participate. Persons with a disability often stay at home and experience a lot of stress. All the energy is focused on their financial situation. Inclusion becomes an illusion. Three strategies are discussed with (1) a role for the government; (2) the care organisations and the municipalities on the local level and (3) the role of persons themselves (empowerment).

### O – 02

**Art of portraiture**
Elisabeth de Schauwer
Centre for Disability Studies and Inclusive Education, Ghent University, Ghent, Belgium

Unicef Belgium wanted to ask disabled youngsters with serious communicative difficulties and/or multiple difficulties (12 – 21 years old) about their participation in society. This is not possible with a questionnaire. In our research we wanted to open potentialities to build the story of the disabled

youngsters. We have observed, listened and talked with youngsters and important people in their surroundings. We have turned representations of who the youngsters are and how they live into a portrait (Lawrence-Lightfoot, 1997).

We want to present the portrait of Ethan. We meet the people, places, activities, impressions and expectations that are very important to him. His lived experiences guide us through his understanding of the world. His family with 7 brothers and sisters form a very tight and connected network who believe in his capabilities. His portrait delivers an exciting combination of strengths and complex barriers.

Ethan is one of 18 portraits. In our research we analyzed all 18. We read the stories of the youngsters extensively. We have looked for common lines in the very diverse portraits. We have clustered these in the following themes: identit(y)(ies), communication and support of interactions, problems in health, opportunities for education, leisure time, participation in a family, support needs and future prospects.

Participation and communication are crucial for youngsters with serious communicative difficulties. The children are blurring boundaries that are set for them through the school system and their label(s). We recognise what Julie Allan (1999) describes: “Transgression allows individuals to peer over the edge of their limits, but also the impossibility of removing them. (…) They need not to reject their gendered or disabled identities, but can choose to vary the way in which they repeat their performances, cultivating an identity which is always in process.” Focussing on ‘becoming’ is more essential than on ‘being’.

**References**

Allen, J. (1999). *Actively seeking inclusion. Pupils with special needs in mainstream schools.* Falmer Press: London.

Lawrence-Lightfoot, S., & Davis, J.H. (1997). *The art and science of portraiture.* San Francisco: Jossey-Bass.

## O – 03

**Community-based social inclusion of citizens with mental disability and citizens with psychiatric problems; a case study in three different districts in Nijmegen**

Annica Brummel[1,2]
[1] Tandem Welzijn, Nijmegen, the Netherlands
[2] Public Administration, Radboud Universiteit Nijmegen, Nijmegen, the Netherlands

**Aim**

Since 2007 a new law has been introduced in the Netherlands: the Wet Maatschappelijke ondersteuning (Wmo), which states that everyone should be able to participate in society. This law, also affects disabled people in the domains of living and wellbeing. Several studies focused on social inclusion in the neighbourhood, but a perspective from the discipline of care is dominant in these studies. In order to get a better view on community-based social inclusion, a focus is needed of the variety and diversity of the community, especially informal networks and small groups.

**Methods**

In a case study, three most different districts of the city Nijmegen will be compared. The first case study (district Nije Veld) is completed. In-depth interviews were conducted with five respondents with mental disability and six respondents with psychiatric problems. We mapped their social network.
In addition, we assessed opportunities for community based activities and regular facilities (about 170 activities in district Nije Veld). Next, five informal networks and small groups were selected for further in-depth interviews. Finally, participatory observations were made.
The analysis of this data provides citizens and social workers with insight into the opportunities for community based social inclusion.

**Results**

- Most respondents visit facilities in the neighbourhood as a visitor, only two have a role as volunteer.
- Most respondents want to increase their participation in the neighbourhood

- Most of the informal networks and small groups are open for participation of disabled people, only one small group did not see any role in inclusion.

**Conclusions**
In general the respondents felt at home in the district. They do not experience a lot of stigma. The informal characteristics of the informal networks and small groups contributed to social inclusion, as well as the moral values of the district. Barriers in community-based social inclusion were not related to characteristics in the neighbourhood, but were mostly personal related.
Social inclusion is stimulated by inducing some social roles, like being a volunteer or a neighbour. There are some barriers regarding informal networks and small groups. They are not familiar with disabilities and participation at all levels is not always likely.
Care professionals and community professionals and the people and facilities they support are separated. There is a lot of activity in the neighbourhood, although this is invisible. Informal characteristics can contribute to social inclusion, however the same characteristics make these activities and networks invisible.
Some of the respondents stated that the staff could help them participate in the neighbourhood. Some of the informal networks and small groups stated that professionals, should not interfere in the informal structure of the neighbourhood, although it is necessary to improve cooperation.

## *Symposium:* Belonging: Strengths & Barriers II

## O - 04

**Precarious Belonging: Chronic Homelessness and People with Impaired Decision Making Capacity**
Jayne Clapton, Lesley Chenoweth, Donna McAuliffe, Natalie Clements, Carolyn Perry
Population & Social Health Program, Griffith University, Meadowbrook, Australia

**Aim**
This Australian research was based on the premise that people with cognitive impairment who have impaired decision making capacity (IDMC), and who experience chronic homelessness, constitute a vulnerable group of people who, through ineffective responses, drift into states of precariousness that deeply affect their chances of belonging and a meaningful existence. Six research questions were addressed which encompassed the nature of the three states of precariousness (Precarious Living, Precarious Ontology and Precarious Morality).

**Methods**
Four phases were undertaken: (1) an in-depth literature review and conceptualisation of the three aspects of precariousness; (2) Environmental scan of the existing national and international social policy and legislative frameworks; (3) Online surveys of approximately 100 frontline workers in agencies relevant to housing and homelessness; and (4) Focus groups with practitioners and key stakeholders.

**Results**
People with impaired capacity who experience chronic homelessness often have complex and chaotic lives, and our society's capacity to support these people to have improved lives and experience belonging and a meaningful existence are restricted. Support services can serve to exclude rather than include people with complex needs.

**Conclusions**
Three significant conclusions were drawn from this research. These are (1) the conceptual framework of Precariousness provided a useful platform; (2) Housing First strategies and practices were shown to have positive effects; and the need for a shift to a new paradigmatic approach such as a Capability Approach was forecasted; and (3) it was recommended that practices that have taken on various aspects to redress precariousness be recognised and further developed.

## O – 05

**Sharing Limburg – Including people with dementia in a process of cultural reproduction**
Ruud Hendriks[1], Annette Hendrikx[2], Ike Kamphof[1], Aagje Swinnen[2]
[1] Department of Philosophy, FASoS, Maastricht University, Maastricht, the Netherlands
[2] Department of Arts and Literature, Centre for Gender and Diversity, FASoS, Maastricht University, Maastricht, the Netherlands

In collaboration with:
- Desirée Coenen, MA-Sc CAST student, Maastricht University, Maastricht, the Netherlands
- Joël Rabijns, MA-Arts Audiovisuele Kunsten, MAD Faculty, Gent, Belgium / BA Audiovisuele Kunsten, KASK, Gent, Belgium.

**Aim**
This paper presents results of the DSiN project 'Beyond autonomy and language; towards a Disability Studies' perspective on dementia' that aims at a better understanding of how people with dementia can escape dominant cultural imagery and feel more at home in society. It reports on an artistic intervention (i.e. film) in a residential care home for people with dementia. The aim of the intervention was (1) to offer people with dementia, whom you normally would not reach, a beautiful sensory experience, and (2) to create room for these residents to participate in a process of cultural (re)production in passive and active ways.

**Methods**
The Flemish filmmaker Joël Rabijns (Hasselt, 1986) was asked to make three short movies. Visual material was used from the historical film archive of the Venlo-based Limburg's Museum. The film making process was based on artistic principles, and informed by scholarly insights from the DSiN research project. The film images were shared with residents of three psychogeriatric wards over a period of four weeks. Members of the research team watched the films together with the residents and registered their responses. During this phase, the researchers relied on the ethnographic method of participant observation.

**Results**
Two strategies were followed to meet the aims of the project. In order to offer the residents a chance to have a beautiful sensory experience (1), the film did not offer a linear storyline that required cognitive processing or rely on remembrance; instead it played with the rythms and tactile qualities of everyday life in the province of Limburg and invited people to share their feeling of belonging in the *here and now.* In order to offer residents a chance to participate in a process of cultural (re)production (2), their responses were registered, whatever form they took (coherent or not; understandable or not; verbal or embodied, et cetera), and will ideally be integrated in the cultural heritage of the museum. The paper will reflect on whether and how these aims were realized in practice.

**Conclusion**
A sense of belonging for people living with dementia depends on *embodied and affective relations* with the world around them. By aiming at other than cognitive forms of recognition, the film project tried to create room for people to manifest themselves and become part of the shared heritage, without immediately filling that room again with our all too obvious fears and expectations; e.g. without projecting *our* hang-up with memory on them. The search for ways to translate such ideas to practice has only just begun.

## O – 06

**Autism and the art of communication**
Mathieu Pater, Aaltje van Zweden - van Buuren
Stichting Papageno, Laren, the Netherlands

**Where we are**
Stichting Papageno aims to engender the enthousiasm, skills and knowledge for appreciating human difference by the use of the arts for wellbeing, self-expression and positive social change.
We offer the opportunity to work on real life arts projects such as Ontmoeten (Meeting) MuziekMakers (Music Makers) and Papageno Music Therapy. Music is a universal human form of communication

and has the power to break through language barriers, physical barriers and mental and cognitive barriers, in order to enable contact and communication with others. This communal experience is unique to the art of music.
Therefore, since 2007, Papageno has been developing its Ontmoeten projects, in which young people, under the supervision of musicians and artists, work with a symphony orchestra to produce and perform their own music theatre performances.
The aim of Papageno MuziekMakers is to help musicians, teachers and caregivers to give children with disabilities the opportunity to express themselves through music and to participate successfully in a musical activity with others.
Papageno also offers music therapy for children for whom it is not (yet) possible to participate in music education in a group.

**Wishes**
In order to realise the best possible art experiences for children with autism and other disabilities, art teachers, creative therapists and specialists must display a willingness to share their expertise and work space for the purpose of developing interdisciplinary objectives. Additional research should be able to stimulate the development of methods and show which assignments degree programmes could incorporate in order to develop a clear concept, policy plans and educational directions that would ensure the continuity and quality of art education for pupils with special development requirements.
Children (both with and without autism and/or or other disabilities) should be offered the opportunity to work in laboratory-like settings to engage them in art activities under the supervision of excellent instructors, in a situation that allows scope for experimentation in an open dialogue with students of art education and creative therapy, artists, teachers, and normally developing children.

**Good Practices**
By monitoring the projects Papageno has acquired vast knowledge and experience. This expertise comprises the foundation block for all further developments, as well as for the training and coaching of the professionals wishing to work with children with autism.
During the presentation you will see and hear about practical examples of how these projects have been received by the teachers and students within special needs education. Further to the observations made and by monitoring the projects, Papageno is overwhelmingly convinced of the positive effects of arts education for children with autism.

## *Symposium:* Representation

## O – 07

### When "awareness" becomes stigma: Representations of autism in charity campaigns and the media, and their impact on people with autism

Mitzi Waltz
The Autism Centre, Sheffield Hallam University, Sheffield, UK

**Aim**
To analyse representations of autism in charity campaigns, and consider the potential impact of these on the lives of people with autism.

**Methods**
Textual analysis of charity campaign materials, application of Hevey's (1992) framework for analysis of stigma production in media representations of disability, interviews with charity and advertising professionals involved in creating these campaigns, and analysis of UK Advertising Standards Authority data on how complaints about campaigns seen by self-advocates as producing stigma were handled.

**Results**
Representations are described and analysed in multiple ways. They are then related to public policy decisions and problematic constructions of autism in professional literature and media narratives, including discourses that have resulted in or excused abuse and violence towards individuals with autism.

**Conclusion**
There is a dark side to campaigns for 'autism awareness,' if their true impact is to place people on the autism spectrum as objects of fear, distress, and concern over cost to the public purse. A campaign co-created with autistic adults was significantly different than other appeals, leading to the conclusion that such involvement may prevent stigmatising discourses.

**Selected references**
Barnett, J., and Hammond, S. (1999) "Representing disability in charity promotions," *Journal of Community and Applied Social Psychology,* 9(4): pp. 309–314.

Darke, P. (2004) "The changing face of representations of disability in the media." In: Swain, J., French, C., Barnes, C. and Thomas, C. [eds.] *Disabling Barriers--Enabling Environments*, 2nd edition. London: Sage: pp. 100-105.

Hevey, D. (1992) *The Creatures Time Forgot: Photography and Disability Imagery*. London: Routledge.

## O – 08

**Who Makes the Portrait? Whose Portrait is it? Portraiture as Interplay between Participant, Portraitist and Audience**
Katrien de Munck, Geert van Hove
Disability Studies and Inclusive Education, Ghent University, Ghent, Belgium
Steunpunt Inclusief Hoger Onderwijs (SIHO) / Support Centre for Inclusive Higher Education, Brugge, Belgium

**Aim**
The Support Centre for Inclusive Higher Education (SIHO) supports the Flemish higher education (Belgium) to become inclusive. SIHO is led by the UN-Convention on the Rights of Persons with Disabilities and works from a Disability Studies perspective.
To support all the Flemish higher education institutions our three main tasks are service provision, networking and research.
When we started in 2008 we discovered that in the material and the research available in Flanders, the perspective of students with disabilities was missing completely. We saw it as our responsibility to inquire the perspectives of students with disabilities, to learn from their experiences, to get in-sight.
After a first qualitative research project (n=9) we felt the need for a method that did right to the complexity of the phenomenon of disability in higher education.
In this way we discovered the arts-based research method Portraiture.
Discovering Portraiture as a method allowed us to inquire the perspectives of students and professionals with disabilities. Research through Portraiture is driven by the dialogue between art and science, by mingling research and activism, by combining rigor and creativity. A portrait always contains a layered narrative and a creative or artistic component.

**Methods**
Since 2009 we used the method of Portraiture (Lawrence-Lightfoot & Davis, 1997) in a combination of contexts (the course on Disability Studies and the course on Interpretative Methods of Research at Ghent University, the course on Inclusive Education at the Vrije Universiteit Brussel; and a research project for SIHO, the Support Centre for Inclusive Higher Education).
The space and time for research is limited within SIHO. By supporting students in the above mentioned courses to work for SIHO, we created with them 38 portraits of students or professionals with a disability. There are 3 series of portraits: portraits of students with a disability studying in higher education, portraits of students with a disability on international exchange and portraits of professionals with a disability who are at work after graduating from higher education.
Our main research aim was to understand the perspectives of students and professionals with a disability and to understand the complexity of disability. As a side-effect we learned a lot about the process of Portraiture. As reflective practitioners, we reflected critically during the process of Portraiture, together with the students that functioned as the portraitists and with the people who were portrayed. We had email contact, face to face intervisions and a virtual platform to exchange experience. Through that we inquired ourselves on who's making the portrait, on whose portrait it is, and on what happens between the portraitist, the participant and the audience.

**Results**
We discovered that driven by the Disability Studies framework, we gave an extra twist to the method of Portraiture. The participant is given the lead of the research process and the design of the portrait. All of the 38 portraits are unique, which we will show in the presentation. In every portrait the design of the artistic component originates from the person who's portrayed. The researcher doesn't decide. Portraiture feels very intense, the method is clear, but very open and doesn't have very strict or practical guidelines. The researcher and participant have to dare and search together. One cannot make the portrait without the other. The portrait can only be made in close and horizontal relation between researcher and participant.
When the portrait finds its way to an audience, meaning-making naturally happens through a similar kind of interplay between 'portrait and audience'. The intimacy of the 'portraitist participant'-relation flows over to the audience, who gets connected and engaged in an embodied understanding of the portrait.

**Conclusions**
The method Portraiture fits our need for a research method to that does right to the complexity of the phenomenon disability. It gives all the space to include the missing perspectives of people with disabilities in practice, policy and research.
Next to that, as researchers with a Disability Studies perspective we added a valuable approach to research through Portraiture. All portraits get co-constructed in an intense intra-action between the 'so called participant' and the 'so called researcher'.
Portraiture 'in a Disability Studies version of the method', is all about becoming and belonging. One becomes (an)other in several ways. Where we originally thought of inquiring insider perspectives of students or professionals with disabilities, we discovered that inside and outside are no discrete concepts anymore, neither for researcher, participant and audience.

**References**
Lawrence-Lightfoot, S. & Davis, J.H. (1997). *The Art and Science of Portraiture.* San Francisco, CA: Jossey-Bass.

## O – 09

**"Does my daughter really belong in our society?"**
Sandrien Banens
Mother of two children, Matthijs -11- and Quirine -9-. Quirine has a mental handicap;
Houten, the Netherlands

I wrote this 'non academic' abstract straight from my heart, as a mother of a mentally retarded (and very social and sweet) nine year old. The theme "the art of belonging" struck me, because it is something I experience every day of my life. Apparently, struggle is necessary to make my daughter belong in this high standard society, every day. As long as we live, we will fight for it.

My daughter was described as 'a cute little toddler, with un uncomprehended mental retardation'. That was more than 7 years ago. Now, the actual description is: 'a cute 9 year old with a mental handicap. Her IQ score is estimated at 35'.

Before I was the mother of a mentally handicapped child, it was easy to say, that '*ofcourse handicapped persons belong, like everybody else'*. And I just went on with the things I was doing. I say this to make clear that if you're not in any way related to handicapped people, it is hard to understand, what it actually means in daily life. To really *make* them belong, different kinds of measures are needed. It is not plain sailing!
The moment my daughter does the things any ('normal') child does, the problems begin.
For example:

- My daughter goes to a specialized school. This school is situated in Utrecht and we live in Houten, therefore she needs special transportation. There the bureaucracy starts: the city council has to decide (every year!) whether my daughter is allowed to use special transportation to go to school.

- My daughter likes to play outside, but it is impossible to let her play without constant guidance. So every two weeks we bring her to a special place where she can safely play with other children. Before we could bring her there, we needed special authorization (every 2 years).

The moment you want your handicapped child to do the things all children normally do, first you have to climb *the bureaucracy mountain*. For me the underlying message is: your daughter does not belong, she is a problem, she costs money.
My daughter as a problem, isn't that the opposite of belonging?

So many more things I could write down about the theme "art of belonging". On different levels we feel that "belonging" is not a natural thing for 'handicapped people'; 'normal' people' staring at us, at her, all kinds of questions we are asked, and some of them hurt: "have you ever thought of ending her life, after she was born?". "Isn't it better for her to stay in an institute for mentally handicapped people?" So much ignorance! And, the choices of politics: no more school swimming for mentally handicapped, no more school camps, no more specialized gymnastics instructors for handicapped children, so much difficulties with transport from home to school, and so many other things.
I do not know much about the situations in other countries, but in the Netherlands, we feel a 'rough wind', as soon as we speak and try to negotiate about facilities which are needed to make participate handicapped people in society, so they belong.

## *Symposium:* Inclusive Relations

## O – 10

**Transitions: a journey through child-based health services to adult services - a personal account**

Josh McDonagh
Bristol, UK

I am a young man (20 years old) who has cerebral palsy with learning and physical disabilities. I am currently studying a BSc in Architectural Studies at Cardiff University, Wales, United Kingdom.

The presentation will focus on my experiences of health services and how they have impacted on my life. I will provide examples of events which had a particular impact.
Over the past 20 years I have accessed many different health services ranging from community-based medical services to specialist services, for example a Pain Clinic. My journey from pre-diagnosis as an infant to accessing adult-based health services will be shared. The impact of services on:

- health and well-being
- family life
- education
- independence

will be explored against a backdrop of services being provided that I didn't need and having to 'fight' to gain access to those services that were needed.
The challenge of asserting my right to have a 'voice' and be listened to will be discussed providing examples of exemplary practice and less than desirable practice.
I will conclude by briefly sharing the frustration of health and social services failing to accommodate my disabilities and how this affects my independence and privacy.

The presentation will be delivered verbally with the aid of a Power Point presentation.

## O – 11

**iSupporter**
Mario Nossin, Anouk Bolsenbroek
Perspectief, Utrecht, the Netherlands

The iSupporter is an instrument for facilitating change in support organisations by cocreation. It aims at developing inclusive support practices, so that people with disabilities can live meaningful, inclusive lives in their own neighbourhood. The development of this instrument is still going on in pilot projects.

The iSupporter has four elements:
A. A cyclic model for structural change which enables teams to take action for improvement concerning their own priorities.
B. An instrument of large Scale Listening and real time monitoring of change.
C. A method for evaluating own practices
D. A toolkit for capacity building and 'collective visioning'

Seven support organisations organized in the 'Network Professionals and Inclusion', working together, started their own pilot. In each pilot a team consisting of people with disabilities, their networks and support workers, community members and policymakers works to facilitate belonging and contribution, community building, reciprocity and support, countering of stigmatization in their own community. The iSupporter combines improvements in the life of individuals with improvements in the community as a whole.

This presentation shows how the iSupporter works. The examples come from the activities of several teams of support organisations collaborating in the network 'Professionals and Inclusion'. In this network participate also two centers of expertise and two universities of applied sciences.

## O – 12

**"Andreas is a child in MY class!"**
**Developing a support concept for teachers while working with diverse students**
Inge van de Putte, Elisabeth de Schauwer, Lien Claes, Katrien de Munck, Geert van Hove
Ghent University, Disability Studies and Inclusive Education, Ghent, Belgium

**Aim**
More children with special needs go to regular schools in Belgium. The special needs coordinator (SENCO) supports teachers in adapting their approach so all children can participate. Teachers look at SENCOs as experts and expect quick answers and disability knowledge. In order to meet this expectations SENCOs give advice and take over tasks but on the long term the participation and belonging of the child doesn't increase.
Our research project wants to develop a support concept where teachers see the student with special needs as part of their class group and take responsibility in developing actions that increase the belonging and participation of the students.

**Method**
Through action research five SENCOs developed a support concept. Teachers are seen as researchers, developers and evaluators. The SENCOs support is given not to compensate, but by being aware that the teacher keeps the control and gets more agency in working with the child with special needs. The SENCO is a critical friend, who facilitates the reflection by using a framework were belonging is a main concept. The focus is not on the impairment but 'on the child in context'.

**Results**
By data triangulation (observation, interview, scale of 'Well being and participation') a positive outcome was measured for the child with special needs.

**Conclusions**
The SENCO needs to be aware of his position. Is he an expert or a critical friend?
It is of great importance that the SENCO *supports the reflection- in- dialogue*, where the teacher develops actions wherefore the child gets a place in the classgroup.

## *Symposium:* Making Inclusion Work

## O – 13

**The art of belonging: about initiatives, limits and possibilities of belonging of disabled people: two messages**

Coleta Platenkamp
CCC Foundation, Amsterdam, the Netherlands

**Aim**

I would speak about a double message that goes with the art of belonging:
1. There is not one way of showing the art of belonging, but many ways, there is diversity. You can read about them in many ego documents where disabled write about their lives. The ways of belonging differ not only because there are different diseases and handicaps, they vary in many context, with kind of people, networks, families, support etc. .
2. Each form of belonging asks different competences, essential to make it possible that belonging will succeed. It is necessary to know limitations and own limits, you need to organize well, show what is possible, have opportunities etc.

**Method**

In an oral presentation I would like to use YouTube videos to have discussion about the double messages showing ways of life, limitations, possibilities and actions in trying to belong in a variety of contexts. Use Dutch examples and examples from abroad as well. Initiatives of Joost Nauta or Anne Mreijen, limitating fatigue of people with Crohn disease, comedians like Boys on Wheels, Josh Blue, the Zimmers, the video 'See me'.

**Results**

They show diversity: what works for one person, won't for another. They show disabled and nondisabled people multiple ways of belonging on different parts of life

**Conclusion**

Learn of what we see and combine that with the two messages. .

## O – 14

**Mobility, incontinence, and social functioning of children with spina bifida in Uganda**

Femke Bannink[1], Geert van Hove[2]
[1] Ghent University, International Federation of Spina Bifida and Hydrocephalus Uganda office, Kampala, Uganda
[2] Ghent University, Faculty of Psychology and Educational Sciences, Disability Studies, Ghent, Belgium

**Aim**

To describes disability specific factors affecting social functioning of children with spina bifida in Uganda.

**Methods**

In total 132 parents of children with spina bifida between 4 and 14 years of age were interviewed in 5 locations. A questionnaire and selected sub-scales of the Vineland Adaptive Behaviour Scales, and the Strengths and Difficulties Questionnaire were used to measure daily functioning, emotional and social functioning, and relationships with peers. Regression analysis was carried out using SPSS16.

**Results**
Average age of the children was 6 years, 43.2% were female, 63.6% need assistive devices: 29.8% used a wheelchair, 21.4% crutches, 6.0% walking frames, and 42.9% crawled due to lack of access or use of a device. The majority is incontinent (89.4%), and practices clean intermittent catheterization (75.8%). In total 56.1% goes to school compared to 83% nationally; on average children are a year behind their age mates. Children with lower daily functioning skills scores, and non managed incontinence had significantly more difficulties with social and peer relationships. No difference was found between children in and out of school. Children whose parents participated in self help groups had significantly better social scores.

**Conclusions**
Almost half of the children in need of assistive devices do not have access to these. Most of them are incontinent and practice clean intermittent catheterization. To improve social participation of children with spina bifida interventions need to focus on provision of relevant assistive devices, improving daily functioning skills, use of catheterization, and promoting participation in parent support groups.

## O – 15

**Inclusion and Self-determination**
Anouk Bolsenbroek[1], Willy Calis[2]
[1] Perspectief, Utrecht, the Netherlands
[2] Vilans, Utrecht, the Netherlands

**Aim**
The project 'Inclusion and Self-determination' aims at giving people with multiple physical and intellectual disabilities a say in living their own life and an equal position in society.

**Methods**
Five teams from different support organizations participated in the project, using instruments and methods from the 'VeranderKIZT', a box with tools for achieving change concerning Quality of Life, Inclusion and Self-determination. The combination of person centered planning and Social Role Valorization on the individual level and system change and the use of a cyclic model on an organizational level, proved to be a sound foundation for achieving success in these areas.

**Results**
The project resulted in big changes in the lives of people with multiple disabilities. One of them, who spent his live in his bed box most time of the day, is now a member of a community garden. Another member shares his garden with him. He works also as a teacher assistant of a drama group. A woman who participated in the project now works in a childrens playgroup. Professionals gained experiences with using the tools and principles of the 'VeranderKIZT'. Others hearing stories about the success of this project where encouraged to do the same.

**Conclusions**
With the help of the 'VeranderKIZT' people enthusiastically join forces for full meaningful and inclusive lives for people with multiple disabilities.

# Stream: (Family) Quality of Life

## *Symposium:* Family Quality of Life

## O – 16

**Family Quality of Life: International Comparisons of 18 Studies in 14 Countries**

Ivan Brown[1], Preethy Samuel[2], and Barry J. Isaacs[3]
[1] Brock University, St. Catharines, Canada
[2] Wayne State University, Detroit, USA
[3] Surrey Place Centre, Toronto, Canada and Brock University, St. Catharines, Canada

**Aim**

Family quality of life is a topic that has garnered strong interest over the past decade. Numerous studies have been carried out in countries around the world. Data from 18 such studies in 14 countries that used the same survey and the same data variables is compared to ascertain similarities, and differences among countries and samples.

**Methods**

Researchers all used the *Family Quality of Life Survey* to collect date, the same data variables for data entry, and SPSS for data analysis. The projects, funded and administered within their own countries, featured a variety of samples of families that have a member with an intellectual disability. The main outcome measures were plotted on a series of charts to illustrate similar and dissimilar measurement trends among countries.

**Results**

The trends across the nine domains and the six measures of the *Family Quality of Life Survey* are remarkably similar among the 18 studies. Only one domain, Support from Services, shows notable differences among countries, although this did not correspond well to whether services were available. Family Relationships was the domain universally rated as contributing most to family quality of life. Support from Other People, surprisingly, was rated lowest by family members in all countries.

**Conclusions**

The results of these studies suggest that families around the world assess their family quality of life in ways that are much more similar than different. The roles of services and others outside the immediate family need to be re-examined for their value to family quality of life.

## O – 17

**Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families**

Lieke van Heumen[1], Alice Schippers[2], Jolanda Kleine[3], Zia Steinbach[3], Anice Adel Nikkhooij[3]
[1] Institute on Disability & Human Development, University of Illinois, Chicago, USA
[2] Stichting Disability Studies in Nederland, Amersfoort, the Netherlands
[3] Windesheim University of Applied Sciences, Almere, the Netherlands

**Aim**

The current study evaluates the long term impact of a project in which families were individually supported in the realization of personal future plans in the city of Almere, the Netherlands (2004-2006).

**Methods**

The study used fourth generation evaluation principles (Guba & Lincoln, 1989). Data collection consisted of semi-structured interviews with family members and adults with intellectual disabilities as well as of focus groups with both groups. Photo voice was used as an accessible strategy to actively engage the participants with intellectual disabilities in the research process (Wang, 2005). The results of the photo voice were presented to stakeholders in the wider community at a town hall meeting.

**Results**
The majority of the participants evaluated the project as having a lasting positive impact on their quality of life. Family members were enabled to better advocate for the young adult with a disability as they learned to think outside the box. As a result of the project they also better incorporated the individual preferences of their family member with a disability. They voiced concern about the limited timespan of the project, the inaccessibility of the society and the quality of residential care. The adults with intellectual disabilities evaluated the project and their quality of life mostly positive, but were also concerned about their safety and experienced inaccessibility and exclusion.

**Conclusions**
Effective support in individual future planning needs to be family-oriented. In order to be successful in supporting the quality of life of this population, the society needs to become more accessible and barriers to meaningful inclusion need to be removed.

**References**
Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation.* London: Sage Publications, Inc.

Wang, C. C. (2005). *Photovoice: Social change through photography.* http://www.photovoice.com/method/theory.html

## *Symposium:* Family & Disability Issues

## O – 18

**Understanding Disability Belief Systems: Family Perspectives and Impact**
Nina Zuna, Meredith Brinster
The Meadows Center for Preventing Educational Risk, The University of Texas at Austin, Department of Special Education, Austin, USA

**Aim**
Little is known about disability belief systems from families' perspectives and how it impacts their actions, family interactions, and well-being. Data from five focus groups on family quality of life were analyzed to extract themes on disability awareness and disability belief systems.

**Methods**
Five focus groups were conducted with a total of twenty-four families of children with autism and I/DD. The focus groups were conducted on the topic of family quality of life. Grounded theory was the methodological procedure. Analysis included the constant comparison method to compare data against data and across transcripts. An inductive analytic approach was used in which data was organized/coded to develop overall themes.

**Results**
The overall themes are:
- Disability beliefs: Society and Community
- Disability beliefs: School
- Disability beliefs: Informal Networks
- Disability beliefs: Family Systems

**Conclusions**
Two important key recommendations from this research are to provide opportunities for professionals to evaluate their own belief systems about disability and listen intently to families' belief systems to understand how it might impact the provision of services and supports. Professionals also need to understand how partnerships with families can be highly emotional; they should frequently take time to reflect to ensure they understand the family's perspective. More attention needs to be directed to the study of the impact of disability belief systems in family-professional partnerships and in the training of disability professionals.

## O – 19

**Working with parents of children with a disability – a continuing dialogue**

Elisabeth de Schauwer
Centre on Disability Studies and Inclusive Education, Ghent University, Ghent, Belgium

**Aim**

While working with mothers and fathers of children with disabilities within the field of inclusive school projects for the last ten years we agree with Ryan and Runswick-Cole (2008) when they state that "there should be a greater engagement with and recognition of the role mothers (and fathers) play in negotiating disability issues" (p.199).
Ferguson (2001) and Landsman (2002) claim that we need to give attention to stories of mothers and fathers of children with a label in order to oppose to 'old' professional interpretations of families (Ferguson, 379-384) - like the 'neurotic parent', the 'suffering parent', the 'dysfunctional parent' or the 'powerless parent'- or 'new' interpretations that position reactions and strategies of parents as constraints within their children's lives, limiting their children's opportunities and aspirations (Ryan and Runswick-Cole, 2008).

**Methods**

The metaphors for this article were gathered by using the 'key incidents' method (Emerson, 2004). Key incidents are events or observations that help to open up significant, often complex lines of conceptual development (Emerson, 2004, p.456). It is a research strategy that is coupled to ethnography from the actual experience of many ethnographers that their analyses were strongly shaped by particularly telling or revealing incidents or events that they observed and recorded (Emerson, 2004, p.459). This 'interest' is not a full-blown, clearly articulated theoretical claim, but a more intuitive, theoretically sensitive conviction that something intriguing has just taken place. These key incidents are helpful for a naturalistic analysis that is necessarily open-ended and emergent, tied to and deriving from specific pieces of what has been seen, heard and recorded (Emerson, 2004, p.458). It helps moving back and forth between observations (here: images and metaphors) and theory (here: about parenting and children with disabilities and about power mechanisms between professionals and parents).

**Results**

We worked with: the traveler, the warrior, the builder of bridges, the discoverer, the trainer/teacher, the in-betweener and the manager. We will position these metaphors as tools parents are using in their confrontation with normalising discourses of disability and education.

**Conclusions**

In this sense mothers and fathers of children with special needs can be seen as 'parents on the margin' from whom we can learn a lot about parenting in general. We move like Campbell (2009) is suggesting from a focus on disability to a focus on the effects of internalisation of ableism.
First and foremost we want to stress that we do not want to judge the value of any of the metaphors. It is not about the right or wrong choices made by fathers/mothers here, but about attitudes and choices that are needed to make it possible for the fathers/mothers 'to live through another day'. Together with Read (2000) and Fisher and Goodley (2007) we claim that the decisions parents are making for their children should get more appreciation (and should be seen as more than just as a collection of day-to-day pragmatic choices) due to the fact that the choices and decisions are grounded in and responsive to the complexities of the context. In that sense the metaphors we will present can be situated as a meta level parents present in their continuing process of reflection on their living together with their children with disabilities.

**References**

Campbell, F.K. (2009). *Contours of Ableism. The production of Disability and Abledness.* Basingstoke: Palgrave Mac Millan.

Emerson, R.E. (2004). Working with 'Key Incidents'. In C. Seale, G. Gobo, J. Gubrium & D. Silverman (Eds.), *Qualitative Research Practice* (pp. 457-472). London: Sage.

Ferguson, P.M. (2001). Mapping the family: Narrative patterns in family portrayals of disability. In G. Albrecht, K.D. Seelman & M. Bury (Eds) *Handbook of Disability Studies* (pp. 373-395). Thousand Oaks, CA: Sage Publications.

Fisher, P. and Goodley, D. (2007). The linear medical model of disability: mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness*, vol. 29, issue 1, pp. 66-81.

Landsman, G. (2002). Emplotting children's lives: developmental delay vs disability. *Social Science & Medicine*, vol 56, issue 9, pp. 1947-1960.

Mortier, K., De Schauwer, E., Van de Putte, I., & Van Hove, G. (2010). *Inclusief onderwijs in de praktijk.* Antwerpen: Garant.

Read, J. (2000) Disability, the Family and Society. Listening to Mothers. Buckingham UK: Open University Press.

Ryan S., Runswick-Cole K.A. (2008). Repositioning Mothers: Mothers, Disabled Children and Disability Studies. *Disability and Society*, vol.23, no.3, pp.199-210.

## O – 20

**Parents' concerns about their child's doing, being, becoming and belonging**

Barbara Piškur[1-3, 8*], Anna J.H.M. Beurskens[1,4], Marian J. Jongmans[6-8], Marjolijn Ketelaar[5,8], Rob J.E.M. Smeets[3,9]

[1] Centre of Research Autonomy and Participation for persons with a chronic illness, Zuyd University, Heerlen, the Netherlands
[2] Department of Occupational Therapy, Faculty of Health and Care, Zuyd University, Heerlen, the Netherlands
[3] Department of Rehabilitation Medicine, CAPHRI, School for Public Health and Primary Care, Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands
[4] Department of General Practice, Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands
[5] Rudolf Magnus Institute of Neuroscience and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and Rehabilitation Center De Hoogstraat, Utrecht, the Netherlands
[6] Department of Special Education, Faculty of Social Sciences, Utrecht University, Utrecht, the Netherlands
[7] Department of Pediatric Psychology, University Medical Center Utrecht, Wilhelmina Children's Hospital, Utrecht, the Netherlands
[8] Partner of NetChild, University Network for Childhood Disability Research in the Netherlands, the Netherlands
[9] Adelante Centre of Expertise in Rehabilitation, Hoensbroek, the Netherlands

**Aim**

For children, social participation is a process of social development and growth; children develop and perceive their own individuality within their community and gain skills to communicate with other people. It shows the degree to which a child participates in a broad range of social roles and relationships. Children with a physical disability experience restrictions in social participation, mainly caused by the environment. Support of the social environment, in particular parents, is crucial for successful social participation. Little is known about how parents contribute to their child's social participation. This study investigated parents' actions, challenges and needs while enabling social participation of their child with a physical disability.

**Methods**

A literature review, a diary method and a survey were conducted.

**Results**
The three studies resulted into an extended overview and new knowledge of parents' actions, challenges and needs. The findings indicate that parents are very concerned with their child's doing, being, becoming and belonging. Doing provides mechanisms for social interaction. Parents often choose activities that fit their child's abilities and enable social interaction with peers. Being is about being true to ourselves and what is distinctive about us that we can bring to others as part of our relationship. Parents often see challenges for their child to engage in activities to be truly himself/herself (being) or to develop their interests and capacities (becoming). A sense of belonging seems the most important concern for parents; how to support their child to be part of society and not being isolated. During this presentation several examples of parents' actions, challenges and needs while enabling their child's social participation in daily life will be shown.

**Conclusions**
Bearing in mind that parents have the foremost influence on social participation of children with a physical disability, meeting their individual needs while supporting their child's doing, being, becoming and belonging should become an objective for service providers and policy makers.

## *Symposium:* Belonging & Quality of Life

## O – 21

**Family support and public policy**
H. Rutherford (Rud) Turnbull
The University of Kansas, Lawrence, Kansas, USA

**Aim**
The purpose of the research is to explain and elaborate on the concept of family support, with emphasis on its conceptual, theoretical, research, and resource issues.

**Methods**
This research is based on analysis of laws, policy documents, and financial data in the United States.

**Results**
The research indicates that the difficulties in securing state or national family support policy derive from three sources: the lack of a consensus definition of family support, the failure to justify it theoretically as a contributor to family quality of life, and the lack of agreement about how to determine whether it is effective in contributing to family quality of life.

**Conclusions**
The research community, in alliance with the practice and advocacy communities, must first reach a consensus about the conceptual, theoretical, research, and resource issues before they reasonably can expect state and national governments to support families any more powerfully than they do no; and the international research, practice, and advocacy communities can contribute to the U.S.'s efforts by offering their knowledge about those issues.

## O – 22

**The application of the oriental dance to persons with intellectual disabilities**
Anamarija Žic Ralić[1], Ana Gajnik Vrđuka[2]
[1] Faculty of Education and Rehabilitation Sciences, University of Zagreb, Croatia
[2] Center for the education of children and youth Karlovac, Karlovac, Croatia

**Aim**
Inclusion of people with intellectual disabilities in a popular leisure activity offers the opportunity to gain experience of equality, inclusion and belonging. The aim of this paper is to investigate the application of oriental dance to persons with intellectual disabilities.

**Methods**
The study involved seven adults with intellectual disabilities who have chosen oriental dance as a leisure activity. Data were collected by interviews, focus groups and observations. Dance workshops were carried out three times a week for three months. People with intellectual disabilities could: express personal preferences, raise the awareness of their own body, adopt and practice the skills of oriental dance, achieve better mobility, coordination, posture, lateralization and spatial orientation and make independent decisions.

**Results**
All users of the program persisted to participate until the end of its implementation and have expressed positive experiences during and after the belly dancing program. Adopted new skills, as well as reducing body weight resulted in a sense of pride that users express at the end of the program.

**Conclusions**
The oriental dance provides opportunities for the development of personal identity and sense of belonging. Engaging currently popular leisure activity, gives people with disabilities a sense of belonging to the group where they have acquired the oriental dance, to a community engaged in the oriental dance, as well as to the wider community where the activity is positively valued.

## O – 23

**What can positive psychology contribute to enhancing the quality of life of persons with (intellectual) disabilities?**
Wil H.E. Buntinx
Governor Kremers Center, Maastricht University, Maastricht, the Netherlands

**Aim**
Quite some time after the disability field moved away from a pathological to a socio-ecological and quality of life approach, a similar paradigm shift took place in psychology resulting in a flourishing subfield within behavioural sciences. We will explore the possibilities of 'Positive Psychology' to making inclusive supports practices more effective.

**Methods**
An analysis of positive psychology literature in the tradition of Martin Seligman c.s. and of the contributions to the 'Oxford Handbook of Positive Psychology and Disability' (edited by Michael Wehmeyer, 2013) has been made. Main findings will be transposed to the field of professional support for persons with (intellectual) disabilities.

**Results**
A summary of assumptions, research outcomes and support technologies that contribute to a crossover of positive psychology and disability support practices.

**Conclusions**
Until now, few efforts have been made to translating positive psychology theory and practice into the field of support for persons with (intellectual) disabilities. We explain how positive psychology can contribute to professional practices that focus on quality of life and life satisfaction of persons with disabilities. It will be demonstrated that professional support practices can benefit significantly from positive psychology theory and practice.

# Stream: Empowerment & Environment

## *Symposium:* Belonging through Performance

## O - 24

**Vulnerability and the disabled body. Getting a sense of belonging through the other**
Ymke Kelders
Graduate student, research master Cultural Analysis, University of Amsterdam, Amsterdam, the Netherlands

**Aim**
The aim of this presentation is to seek for ways to reconceptualise the notion of the disabled body in relation to the changes in the health care system of the Netherlands and the influence of neo-liberal standpoints.

**Methods**
Through an analysis of the PGB (A personal budget from the government for people in need of care, to be able to hire and pay their own caregivers) I will examine the position of the disabled body and the vulnerability that seems to be attached to this body. The poem “the dance of day” will be used as an illustration of the dependency of a disabled body but will also show the potential of getting a sense of belonging through the other.

**Results**
The PGB and the poem show the dependent relation that a disabled body can have when it needs care. A reconceptualization of vulnerability, dependency and responsibility is necessary when looking at a disabled body in society.

**Conclusion**
The changing rules in the health care system of the Netherlands ask a critical gaze that goes beyond the fixation within neo-liberal values that seem to claim that “we all have something”, and demand on being self-sufficient.

## O - 25

**Technical aids, aesthetics and the mediation of belonging**
Hilje van der Horst, Maartje Hoogsteyns
Research Centre Sociology of Consumers and Households, Wageningen University, Wageningen, the Netherlands

**Aim**
Technical aids for people with impairments are usually evaluated with medical and functional terms. For example, the absorptive capacities of incontinence material need to be sufficient. Hearing aids need to increase hearing. Despite the dominance of such forms of evaluation, all technical aids also have aesthetic effects on users and their social environment. In this paper we analyse how aesthetics of technical aids influence the way a user can relate to his/her aid, to the impairment and to others in diverse social settings.

**Methods**
Biographic interviews using the Biographic Narrative Interpretation Method were conducted with 27 persons who (had) used an arm prosthesis, hearing aids or incontinence products.

**Results**
All users of aids elaborately commented on the aesthetics of technical aids. Aesthetics of technical aids were found to intervene in the way in which people could relate to others and to their impairment. Also, when aids were found appalling this prevented a successful appropriation of the object itself. The item, and sometimes the handicap, was not found to ‘belong’ to the body. Abilities to modify or choose a nicer looking item improved this sense of belonging.

**Conclusions**
Aesthetics of an aid interfere in the way in which people achieve a sense of belonging with the aid, the body, as well as within diverse social settings. When people were able to influence aesthetics, either through a choice between aids, or through modifications, they were more likely to achieve such belonging.

## O - 26

**Agency in the 21st century: the emperor's new clothes**
Sander R. Hilberink, Mieke Cardol
Expertise Center Innovations in Care, Rotterdam University, Rotterdam, Netherlands

**Aim**
Ideas about people with disabilities have evolved dramatically since the 1950s. From individuals 'suffering from illness', whilst today's credo stresses social inclusion, participation and agency. However, the definition of agency varies among stakeholders. The present paper explores changing and competing constructions of agency.

**Methods**
We conducted a quick scan of the international literature and national policy reports. Used keywords included 'agency', 'mastery', and 'empowerment' to cover related constructs. Definitions were critically examined regarding their references to having control over one's life, based on choice options between acceptable alternatives facilitating meaningful choices.

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

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

## *Symposium:* Adapting the Environment I

## O - 27

**Avatar: Ableism and Normalization**
Susan Flynn
Equality Studies Centre, University College Dublin, Dublin, Ireland

**Aim**
The aim of this presentation is to prove that the film *Avatar*, now the most financially successful film of all time, is intimately invested in the project of ableism; an ideology that sustains the ‘hegemony of normalcy’ (Davis, 1997).

**Methods**
The method employed for this analysis is a close reading of *Avatar* as text. When examining representations of disability in society, such as those in film, it is necessary to explain the collective elements of the film text; it’s narrative elements, mise-en-scene and editing (Vande Berg & Wenner, 1991).

**Results**
*Avatar* colludes in Medical Model ideologies which seek to ‘fix’ the individual ‘problem’ of disability. The main character’s disability is a totalizing identity that defines and harnesses him. From the very

first comments the audience is positioned to assume that the disabled Sully dreams of mobility and its attendant virility. The dream of release from the constraints of the body is all the more alluring when the body is disabled; such bodies have historically served as a device upon which artistic discourses have leaned (Norden, 1994, Chivers & Markotic, 2010). Data is amalgamated by a scene by scene analysis which exposes an ableist agenda; statistics of the character's position on screen in relation to able-bodied peers is correlated with power dynamics in the narrative. Camera angles and other editorial devices diminish the disabled character in favor of professionally superior others.

**Conclusions**
*Avatar* literally subjugates the disabled body with technology, in the project of creating a new, more vibrant, able world. By celebrating technological advances and reifying science, *Avatar* draws the audience into complicity with the contentious project of 'fixing' disability.

**References**
Davis,L.J. (1997) *The Disability Studies Reader*. New York; Routledge.

Chivers, S. & Markotic, N., (2010) *The Problem Body; Projecting Disability on Film*. Ohio; Ohio State University Press.

Norden, M.F. (1994) *The Cinema of Isolation*. New Jersey; Rutgers University Press.

Vande Berg, L.R. & Wenner, L.A., (1991) *Television Criticism: Approaches and applications*. New York; Longman.

## O - 28

**How to turn technical aids into social mediators?**
Maartje Hoogsteyns, Hilje van der Horst
Dep. Medical ethics, Amsterdam Medical Centre, Amsterdam, the Netherlands

**Aim**
In the last few years, the definition in medical anthropology and philosophy, but also in public discourse, of what is 'good care' has been changing. Partly as a result of the increase in people with chronic diseases, it is shifting away from a focus on 'curing the individual body' towards the more contextual and socially embedded notion of 'how to have a good life with an impairment'. In congruence, the dominance of the concept of autonomy is more and more questioned, as people realize that we are all dependent on others for having that good life (having an impairment or not). The field of technical aids is dramatically lurking behind. Technical aids are still, also in disability studies, predominantly understood in medical-model-terms: they are supposed to 'repair' or compensate for a persons individual impairment, adding to their autonomy. In a future research project we would like to explore how to redefine (and revalue) technical aids from the idea that having an impairment is something that we deal with and experience in relation to important others (people and things).

**Methods**
In this paper, we will first look at the results of 27 biographic interviews with people using arm prosthesis, hearing aids and incontinence pads. What impact did the arrival of this particular aid have on a person's intimate social environment? Secondly, we will discuss the Belgium project 'Design for [every]ONE' in which students Industrial design and occupational therapy work together with a person and his/her family members/care-givers. Jointly they try to build a (costless) everyday assistive tool. How does this co-creation enfold?

**Results and conclusions**
This project is in a proposal-state, so there are no results and conclusions yet to present. However, based on the 27 interviews, we can already infer that the arrival of a technical aid in a home setting can dramatically change relations between family members as well as the definitions and experience of (dis)ability and care. This underlines the importance of revaluing technical aids from an ethics-of-care perspective.

## O - 29

**Creating a positive view**
Petra C. van der Kaa
Balancine, Breda, the Netherlands

**Aim**
Hearing problems are expected to affect only older people. The many young people and children with hearing problems are not being considered. They don't associate themselves with the older people with hearing aids that are portrayed in advertisements. Young people with a hearing impairment act, out of shame, like they are normal-hearing people. This has a negative influence on their self-esteem, health and wellness.
In a sponsored project, Balancine invited people with a hearing impairment to put their ears into the picture by photographing them. The aim is to improve the (self)images of young people with a hearing impairment, to improve their self-esteem and to influence the way society thinks about them.

**Methods**
An art project in which Balancine photographed young hearing aid users in a positive, non-medical way. The ears received positive attention through unique haircuts, makeup, hats and (ear)jewelry. Short and snappy captions are accompanying these portraits to stress the participants individual identity. We portrayed their power and competences and not the impairment.The models were found in the personal network of the author, and by use of the internet, social media and advertising posters.

**Results**
The results will both be shown at the conference and outside of the conference, e.g. in articles, art exhibitions, presentations and on the internet.
The self-image of the models has improved. They felt seen and heard.

**Conclusions**
It is important to take the individual as a starting point. People don't live up to others expectations. It's not possible to make an ideal picture. People need positive attention.They need to be asked what they want, what is important to them. This will have a positive influence on the health and wellness of people with a hearing impairment, and will create a more inclusive society.

## *Symposium:* Adapting the Environment II

## O - 30

**The User-Initiated Design Phenomenon in Stroke Survivors: Adapting Inaccessible Environments**
Martha P. Sarmiento[1,2], Joy Hammel[3]
[1] Facultad de Artes, Departamento de Diseno Industrial, Universidad Nacional de Colombia, Bogota, Colombia
[2] Disability Studies, Disability and Human Development, University of Illinois, Chicago, USA
[3] Joint Doctoral Program in Disability Studies & Doctoral Program in Rehabilitation Sciences, College of Applied Health Sciences, Departments of Occupational Therapy & Disability and Human Development, University of Illinois, Chicago, USA

**Aim**
Design is a basic human activity; everyone who advances actions to change an existing situation into a desired one engages in design. The act of designing thus posits a discussion about the active involvement of "users" in the design process and responds to and integrates user-initiated design. User-initiated design is a phenomenon that many disabled people enact while negotiating their less-than-accessible environments every day but this experience has been neglected from research in the field of design. Given this lack of attention the study explores designs people with disabilities, particularly people who have had a stroke, generate in their home environment and factors supporting them in taking an active role in designing this key living environment.

**Methods**
The study used a comparative case study design to explore user-initiated design in a group of people with disabilities as they strategize to adapt their home environments following a stroke. In addition a participatory approach was used to involve participants in the research process and in generating implications for changing how designers and rehabilitation professionals look at design of everyday living environments and how they could engage disabled people more actively in this process.

**Results**
User-initiated design seems to play an important role in the process of adaptation and ongoing interaction with the environment after the stroke. Their engagement as active agents in the innovation of accessible living environments can increase their sense of competence and enable social participation.

**Conclusions**
Innovative users with stroke actively shape and personalize their environment through user initiated design processes. Their experience and inputs in this process is silent but innovative.

## O - 31

**Culture for Everybody? Museums and Galleries Accessible for Deaf Pupils in the Czech Republic, France and Sweden**
Mariana Koutská
Faculty of Education, Masaryk University, Brno, Czech Republic

**Aim**
Culture is crucial for our identity, the feeling of belonging. It is the keystone of education. There is a group of children though, who are from the education perspective considered as having special needs. At the same time these children represent members of a cultural and linguistic minority. Who are they? They are Deaf. The question remains are cultural institutions accessible for deaf children.

**Methods**
80 deaf primary school pupils and 40 teachers were surveyed on issues related to cultural institutions (terminology, experience, implementation into school education programs). 75 Czech, French and Swedish museums and galleries were questioned about the accessibility for deaf visitors on the level of human resources and technical measures, about programs offered to deaf children and the level of cooperation with the outside network.

**Results**
The results show that deaf children have problems with understanding the basic terminology despite of experiencing multiple visits. Teachers and institutions see the lack of information about deafness as a key factor for better mutual cooperation. French institutions are the only ones offering a variety of programs for deaf pupils by cooperating with deaf staff and using new technologies.

**Conclusion**
I conclude that unlike national legislation and policies, cultural institutions are not enough prepared to welcome deaf visitors. On the other hand, growing number of institutions have employees responsible for accessibility, the number of programs offered for deaf children is increasing and institutions claim they are willing to change their approach toward deaf visitors.

## O - 32

**Accessibility for people with different kinds of disabilities in community organizations in Amsterdam**

Stefanie van Zal
Researcher at the Knowledge and Development Centre for Society and Law, University of Applied Sciences Amsterdam, Amsterdam, the Netherlands

**Aim**

Because of budget cuts in the Netherlands, people with disabilities can no longer apply for individual and professional assistance to participate in society. Therefore, improving accessibility of more general organizations such as community and welfare organizations has become very important. Its challenging to improve accessibility for people with all different disabilities equally. Not all needs for adjustments or help are equally viable or practical. Here the question rises how to provide equal access to people with different disabilities such as physical, intellectual, psychiatric or sensory disabilities.

The local government in Amsterdam has stimulated such organizations to improve accessibility by funding training and stimulating policy changes. In this research these efforts to improve accessibility will be evaluated.

**Methods**

To evaluate the efforts to improve accessibility, both employees and visitors of such community organizations have been interviewed. In total there have been two measurements of group interviews with 70 employees, and three measurements of pre structured interviews with 250 visitors of such organizations. In this presentation I will mainly focus on the connection between the results of the employee group interviews and the theoretical background of the social model of disability and its applicability to certain types of disabilities.

**Results**

Employees of community organizations had great difficulty providing equal accessibility for people with different disabilities. The 3 main difficulties they defined were:
1. Stimulating acceptance and equality for people with stigmatized disabilities among visitors
2. Recognizing and anticipating on invisible or fluctuating disabilities
3. Dealing with people whose disability intervenes with their behavior.

**Conclusions**

These results give an overarching view on why relying on accessibility as a means of social inclusion can be problematic for people with certain kinds of disabilities. Those with stigmatized, invisible or fluctuating disabilities and/or symptoms that intervene with their behavior might therefore be disproportionately harmed by the measure to cut the individual support from the budget and improve accessibility instead.

# Stream: Inclusive Employment

## *Symposium:* Participation through Paid Work

## O – 33

**Can't do it on their own**
**The work participation of young disabled persons in the Netherlands**

Katinka van Brakel, Jolanda van Rijssen, Martijn Wijnhoven
Dutch Institute for Employee Benefit Schemes (UWV), Amsterdam, The Netherlands

**Aim**
Government policies are progressively aimed at work participation of people with disabilities, including young disabled persons. This study therefore aims to determine (1) the degree of participation in paid work by young people with a work disability benefit in the Netherlands, and (2) establish which obstacles and opportunities they encounter in order to get and keep work.

**Methods**
Analyses of the administrative databases[1], complemented with qualitative data.

**Results**
The work participation of young disabled people fluctuates around 25%. However, only half of them was able to maintain their new found work for over a year.

The degree of work participation depends upon various factors: (1) Those that have a focus on work from an early age result more successful. (2) The medical diagnosis correlates with the degree of work participation. (3) Many young disabled people can only work with the aid of a professional job coach, minimum wage dispensation, and/or continuing benefits. E.g., of those that work over 60% need some form of formal aid.

**Conclusion**
Young people with a disability are able to participate in paid work and a substantial amount of them indeed does participate. However, for the majority this is only possible through much effort and formal aid during their entire working life.

**References**
Van Brakel et al. (2102). *UWV Monitor Arbeidsparticipatie 2012. Aan het werk zijn, komen en blijven van mensen met een arbeidsbeperking.* Amsterdam: UWV.

## O – 34

**High prevalence of early onset mental disorders among long-term disability claimants**
Bert Cornelius[1,2,3], Jac J.L van der Klink[1,2], Michiel R. de Boer[1,2,4], Sandra Brouwer[1,2], Johan W. Groothoff[1]
[1] Department of Health Sciences, Community and Occupational Medicine, University Medical Center Groningen, University of Groningen, The Netherlands
[2] Research Center for Insurance Medicine, The Netherlands
[3] Social Security Institute, the Netherlands
[4] Department of Health Sciences, VU University, Amsterdam, the Netherlands

**Aim**
This study aims to provide information on prevalence, mental-mental and somatic-mental comorbidity, age-of-onset, and severity of mental disorders among persons claiming disability after long-term sickness absence. Such information is needed to promote return to work and to prevent unnecessary disability.

**Methods**
Cross-sectional analysis of a nationally representative sample of Dutch disability claimants (n=346). CIDI 3.0 was used to generate lifetime, 12-month and 30-day DSM-IV classifications of mental disorder, age-of-onset and severity; registry data on demographics and ICD-10 classifications of somatic disorder certified as primary cause of disability were obtained.

**Results**
The mean age of respondents was 49.8 (range 22-64). The prevalence of DSM-IV classifications was 69.9% for lifetime, 44.5% for 12-month and 25.4% for 30-day mental disorder. The most prevalent broad categories of mental disorders were mood, anxiety and substance use disorder with a 12-month prevalence of 28.6%, 32.9% and 4.6%, respectively. Mood and most anxiety disorders had ages of onset in adolescence and early adulthood. The phobias start at school age. Of all respondents, 33.7% had ≥ 1 12-month mental disorder. Co-occurrence of substance use disorders, phobias and depression/anxiety disorders are frequent. Urogenital and gastrointestinal diseases, and cancer coincide with 12-month mental disorder in 66.7%, 53.9% and 51.7% of cases, respectively. More than two out of three specific mental disorders are serious in terms of impairment and disability.

**Conclusions**
Disability claimants constitute a vulnerable population with a high prevalence of serious mental disorder, substantial comorbidity and ages-of-onset in early working careers.

## O – 35

**Employment, Social Capital and Community Participation among Israelis with Disabilities**
Tal Araten-Bergman
School of Social Work, University of Haifa, Haifa, Israel

**Aim**
Employment, social capital, and community participation have emerged in recent years as significant concepts for realizing the human rights of individuals with disabilities. Yet the theoretical inter-relationships of these concepts remains largely overlooked, as does the empirical basis for understanding the underlying connections. The current study aims are two fold: first, to explore the relationships between employment status, social capital, community participation and well-being among Israelis with disabilities. Second, to explore the unique contribution of social capital to the well-being and integration of individuals with disabilities.

**Methods**
A total of 274 participants with self-reported disabilities completed a questionnaire containing measures of individual social capital, community participation, well-being and background data. Correlation and univariate analysis were used to compare scores between employed (n=131) and nonemployed (n=143) participants, and logistic regression analysis was conducted to test the unique contribution of employment to social inclusion and well-being.

**Results**
Core findings indicate that employed participants reported significantly higher levels of social capital and were more integrated in leisure and civic activities than their non-employed counterparts. Moreover, employment status was found to have a significant contribution to the variance in the participant's subjective well-being.

**Conclusions**
Acknowledging the importance of social capital for community inclusion may inspire disability advocates to better address the importance of network building as means of promoting social and vocational inclusion.

## *Symposium:* The Essentials of Belonging: Inclusive Employment

## O – 36

**Experiences with the Method 'Inclusive Redesign of Work Processes'**

Gemma M.C. van Ruitenbeek[1], Marike J.G.P. Mulder[1], Fred R.H. Zijlstra[1], Frans J.N. Nijhuis[2], Henny P.G. Mulders[3]
[1] Faculty of Psychology and Neuroscience, Department of Work and Organizational Psychology, Maastricht University, Maastricht, the Netherlands
[2] Professor in 'Inclusive (labor) organization' at the Faculty of Psychology and Neuroscience, funded by the Atlant Groep, Maastricht, the Netherlands
[3] UWV WERKbedrijf, the Netherlands

**Aim**
In this research we investigated the effectiveness and applicability of the method 'Inclusive Redesign of Work Processes' (Dutch abbreviation: methode-IHW). This method aims to facilitate the participation of people with a large distance to the labor market in regular organizations. Based on an analysis of work processes and redesign principles, organizations are enabled to make optimal use of the available work capacity and talent in the labor market. The method turned out to be effective for the creation of suitable work for a large group of people with disabilities in an organization.

**Methods**
Fifty positions were created for the target group in a regular health care organization. A qualitative evaluation approach was used to assess the effectiveness of the work redesign method.

**Results**
The results suggest that the method is effective for the creation of sustainable employment, and that the integration of people from the target group is economically and socially advantageous.

**Conclusion**
Although the method has not yet been widely applied, the results suggest that it can be used in a variety of companies to enable the integration of people with disabilities into the work force. However, it is a complex and labor-intensive method that requires expertise in the execution of the analysis and the assessment of the target group.

## O – 37

**Acceptance of People with Disabilities at Work**
**A literature review and validation of a newly developed questionnaire**

Katharina Vornholt[1], Sjir Uitdewilligen[1], Frans J. N. Nijhuis[2]
[1] Faculty of Psychology and Neuroscience, Department of Work and Organizational Psychology, Maastricht University, Maastricht, the Netherlands
[2] Professor in 'Inclusive (labor) organization' at the Faculty of Psychology and Neuroscience, funded by the Atlant Groep, Maastricht, the Netherlands

**Aim**
A lack of social acceptance is often the reason why employees with disabilities fail to stay in regular organizations for sustained periods. The study presents a coherent review of the extant literature on factors affecting the acceptance of people with disabilities in regular employment. Based on the findings a questionnaire was developed and validated to assess the acceptance of employees with disabilities within a group of colleagues.

**Method**
We conducted a search of the recent literature on the acceptance of people with disabilities at work. In total 40 articles were selected, coded and analyzed. Based on the results a questionnaire on acceptance of employees with disabilities was developed and validated.

**Results**
Results will be presented on the antecedents and consequences of acceptance.

**Conclusion**
The literature review revealed that the concept "acceptance of people with disabilities at work" has never been clearly defined and methodically investigated. We contribute to the literature in three important ways: (1) by developing a definition of acceptance based on classical attitude literature, (2) by creating a literature based framework of antecedents and consequence of acceptance, and (3) by developing and validating an instrument to assess the acceptance of people with disabilities at work. The present study is, therefore, a first step towards the development of a robust measure of acceptance and the identification of factors contributing to acceptance of employees with disabilities.

## O – 38

**The Building Blocks of an Inclusive Climate**
Philippe T. J. H. Nelissen, Ute R. Hülsheger, Gemma M.C. van Ruitenbeek, Fred R.H. Zijlstra
Faculty of Psychology and Neuroscience, Department of Work and Organizational Psychology, Maastricht University, Maastricht, the Netherlands

**Aim**
Inclusive organizations value and target a diverse workforce and therefore aim to include people with disabilities (PWD). Hereby, it is important that coworkers display helping behavior towards PWD (inclusive behavior). In this study, we investigated the boundary conditions of an inclusive climate that foster helping behavior towards PWD.

**Methods**
Eighty-four teams consisting of 372 employees of various Dutch organizations, who work with PWD, provided self-ratings of inclusive climate factors. Helping behavior towards PWD was rated by 313 work colleagues and 92 supervisors.

**Results**
Multilevel random coefficient modeling and linear regression analysis confirmed the link between various individual and team level factors and helping behavior towards PWD.

**Conclusion**
This study shows that inclusive organizations should be aware of the boundary conditions that need to be met in order to facilitate inclusion of PWD. Only if an inclusive climate is present, coworkers will engage in helping behavior towards PWD. Individual as well as team level factors contribute to the extent to which coworkers display helping behavior towards PWD. Organizations can select and recruit new employees on the basis of individual predictors for helping behavior, or train teams and team leaders to create a hospitable environment that stimulates helping behavior towards PWD.

## *Symposium:* Work as Catalyst for Belonging

## O – 39

**Autism Spectrum Disorders and Intellectual Disabilities: Private-Sector Workplace Discrimination in the U.S.A.**
Todd A. van Wieren[1,2]
[1] Indiana University of Pennsylvania, Indiana, Pennsylvania, U.S.A.
[2] The National EEOC ADA Research Project, Virginia Commonwealth University, Richmond, Virginia, U.S.A.

**Aim**
Two groups of Americans with disabilities protected from discrimination in the private-sector workplace by Title I of the Americans with Disabilities Act (ADA) and the U.S. Equal Employment Opportunity Commission (EEOC) are those with autism spectrum disorders (ASDs) and intellectual disabilities (IDs). Because of behavioral/communicative deficits, these individuals may be particularly prone to experience workplace discrimination. Data from the EEOC was analyzed to: 1) describe Title I ADA discrimination charges made by individuals with ASDs/IDs, and 2) compare/contrast the characteristics of ASD with ID cases.

**Methods**
Utilizing all resolved charges of Title I ADA discrimination made to the EEOC from 1992 through 2008, key dimensions analyzed include: charging party demographics, employer industries, location and size of employers, nature of alleged discrimination, and case resolutions. Comparative analysis of the ASD and ID cases was then conducted.

**Results**
First, lower numbers of ASD/ID charges are made relative to other major disability groups. Second, ASD and ID cases are relatively similar to each other. Third, the differences that do exist indicate that ASD charges (v. ID charges) are made by individuals who are younger, more likely to be male, and more likely to be made against certain industries.

**Conclusions**
Reasons and implications for the low numbers of ASD/ID allegations are explored, including the possibility that these individuals and their advocates might not accurately recognize discrimination or fully exercise their ADA/EEOC rights. Second, vocational rehabilitation efforts for people with ASDs/ IDs are explored, considering the descriptive and comparative analysis findings of this study.

## O – 40

**Active inclusion of young people with health problems or disabilities in 11 EU-Member States**
Edwin L. de Vos
CHAMP Advies & Onderzoek, Almere, The Netherlands

**Aim**
The study is based on a research project for the European Foundation for the improvement of working and living conditions (EuroFound), the country report on Active inclusion of young people with disabilities in the Netherlands (www.eurofound.europa.eu/publications/htmlfiles/ef11354.htm) and the EuroFound (2012) overall report (www.eurofound.europa.eu/publications/htmlfiles/ef1226.htm).

The study on behalf of EuroFound examines the situation of young people with health problems or disabilities in 11 countries (Denmark, Finland, France, Germany, Ireland, the Netherlands, Poland, Portugal, Spain, Sweden and the United Kingdom) and at EU level, with an emphasis on assessing the implementation of active inclusion policy at national level. Active inclusion policy seeks to integrate measures in relation to four pillars – adequate income, inclusive labour markets, access to Life Long learning and access to quality services – for people furthest from the labour market. The main aim of the research is to see how the policy has been implemented to move young people with health problems or disabilities from inactivity into employment.

**Methods**
Country reports were produced by researchers in each of the 11 countries on the basis of desk research, selected good practices and interviews. Forty-four diverse and innovative case studies of good practice are analyzed in the overall report to distil the characteristics of service providers, their experiences and the success factors underlying their projects to formulate conclusions that are applicable across the EU. Some of the case studies are dedicated to mental health, a growing concern in the majority of countries that were studied.

**Results**
Young people with health problems or disabilities in the EU have difficulty accessing employment. The limited information available on this group points to very low employment rates and increasing numbers taking up disability and other benefits, either directly from school or early in their working lives. Statistics on the extent of this group are difficult to find – employment statistics do not document the health status of young people, while health or disability statistics do not easily yield information on the employment status of young people. A range of policies at EU level are relevant to the situation of young people with health problems or disabilities, but most significant is active inclusion that integrates measures in relation to the four pillars.

**Conclusions**
Active inclusion policies have limited reference to these young people if, alongside the pillars of adequate income, inclusive labour markets, and access to quality services, it excludes the pillar of education and lifelong learning. Education is a crucial domain for young people facing the transition into employment. Other relevant policies such as those concerned with employment, discrimination and people with disabilities are also potentially relevant, but in most Member States don't specifically target young people with health problems or disabilities.

In the Member States there is a trend towards dealing with the needs of people with health problems or disabilities in mainstream rather than specialist services. Sheltered services still have an important role in a number of countries. Focusing on transitions from schools-based to employment-based systems is an important and productive way of addressing the problems of these young people.

## O – 41

**Key elements in transition from school (VSO) to employment: a survey and a new approach**
Corry Aarnoutse, Veroniek Janssens
Perspectief, kenniscentrum voor Inclusie en Zeggenschap, Utrecht, the Netherlands

**Aim**
Promoting employment on the labor market for youngsters/ young adults with learning difficulties and/or disabilities and supporting better starting positions in schools.

**Methods**
We did a qualitative research in two special schools (VSO) in the Netherlands. Our research question was:
What do youngsters/ young adults, their personal network, and schools need to ensure a successful transition from school to work?
We interviewed ca. 60 students, parents, teachers, employers and other stakeholders.

**Results**
Our research showed there is much to be gained by:
- enlarging the students self-determination together with their personal network;
- more orientation on citizenship, in line with and extending to the vision of the school. Guiding principle is the right of every student to participate in and contribute to society, even when severe handicaps are involved.
- enlarging the network of schools for example cooperating with local/regional business organizations

**Conclusions**
A culture change is needed, as well as extending networks for schools, and having best practices.

# Stream: Friendship

## *Symposium:* Reciprocity & Intimacy

## O – 42

**The possibility of cultivating reciprocal relationships**

Maaike A. Hermsen[1,2], Petri P.J.C.M. Embregts[1,2,3,4], Noud Frielink[1,2], Kim.K.J.H.M. van den Bogaard[1,2], Sara Zwetsloot[1,2], Wietske W.M.W.J. van Oorsouw[1,2] (moderator)

[1] Academic Collaborative Centre Living with an Intellectual Disability, Tranzo, Scientific Centre for Care & Welfare, Tilburg School of Social and Behavorial Sciences, Tilburg University, Tilburg, the Netherlands

[2] Dichterbij Kennisn@, Ottersum, the Netherlands

[3] Department Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands

[4] Faculty of Health and Social Studies, HAN University of Applied Sciences, Nijmegen, the Netherlands

**Aim**

A growing tendency can be noticed to construe professional care in terms of care *relations*. According to the theory of professional loving care, a high quality reciprocal relationship between professional and client affects the provided quality of care. If this claim can be sustained, training and education programs for health care professionals should emphasize the strengthening of relational ties and the development of a professional loving care attitude. However, current training programs mainly focus on the increase of measurable knowledge and the application of *technical* skills and interventions. In the present study, evidence is gained regarding the influence of education on cultivating a professional loving care attitude.

**Methods**

From April 2010-May 2011, two studies have been combined to find an answer to the research questions: is it possible to cultivate or develop a professional loving care attitude and what topics should be addressed in an educational/training context when cultivating a professional loving care attitude in health care professionals will be taken seriously? First, semi-structured qualitative interviews were conducted with 10 training consultants or advisors, teachers, work supervisors and human resource managers. Second, a focus group interview was held with experts, ethicists with experience in teaching ethics and the development of attitude.

**Results**

On the basis of the view that a professional loving care attitude is trainable twelve topics have been addressed by the respondents of the two studies to be able to cultivate a professional loving care attitude. Respondents made a classification concerning the most appropriate moment to address these topics: at the start of the study, during the bachelor/master phase of the study, or (when making the transfer) into practice.

**Conclusions**

On the basis of this study it can be concluded that to optimalize caring relationships can be influenced through training and education. However, in the discussion we will critically reflect on the twelve topics that should be addressed to cultivate professional loving care among (future) care professionals.

## O – 43

**The applicability of motivational interviewing among people with mild to borderline intellectual disability; a self-determination theory perspective**

Noud Frielink[1,2], Petri J.C.M. Embregts[1,2,3,4], Carlo Schuengel[5]
[1] Department Tranzo, Tilburg University, Tilburg, the Netherlands
[2] Dichterbij Kennisn@, Ottersum, the Netherlands
[3] Department Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands
[4] Faculty of Health and Social Studies, HAN University of Applied Sciences, Nijmegen, the Netherlands
[5] Clinical Child and Family Studies, VU University, Amsterdam, the Netherlands

**Aim**
A promising method to increase participation and engagement of people with mild to borderline intellectual disabilities (MBID) in their treatment and care is motivational interviewing (MI). Deploying MI can address the basic psychological needs for autonomy, competence and relatedness, which are essential aspects in both self-determination theory and professional loving care. Social environments (e.g., professionals) can either satisfy or frustrate these needs; supportive social environments that allow need satisfaction should predict autonomous motivation and increased participation and engagement in treatment and care. Autonomy, competence and relatedness are important components in treatment and care and professionals should attempt to satisfy these needs from a professional loving care perspective. However, as far as we know, the need satisfaction among people with MBID has not been subject to research yet. The present study's purpose therefore to identify how professionals could adapt MI techniques and to evaluate need satisfaction.

**Methods**
We conducted semi-structured qualitative interviews and focus groups with 26 clients, parents and professionals to identify adaptations of MI-techniques. To evaluate need satisfaction, 100 adults with MBID were recruited from care organizations in the Netherlands and completed an adapted version of the New Basic Psychological Needs Scale.

**Results**
Recommended modifications to accommodate MI are: adapt to language level, adjust to cognitive abilities and control for social desirability of responding. In addition, certain characteristics of professionals are critical for effective MI. Data collection regarding need satisfaction will take place from May until December 2013. During the presentation preliminary results will be presented.

**Conclusions**
The research is not finished yet, so it's too soon for conclusions.

## O – 44

**Development of an evidence based training focused on sexuality and sexual abuse of people with intellectual disabilities**

Kim J.H.M. van den Bogaard[1,2], Sara Zwetsloot[1], Marianne Heestermans[1], Petri. J.C.M. Embregts[1,2,3,4]
[1] Dichterbij Kennisn@, Ottersum, the Netherlands
[2] Department Tranzo, Tilburg University, Tilburg, the Netherlands
[3] Department Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands
[4] Faculty of Health and Social Studies, HAN University of Applied Sciences, Nijmegen, the Netherlands

**Aim**
In society sexuality of people with intellectual disabilities (ID) has often been ignored, resulting in minimal or lack of adequate assessment and treatment of sexual abuse. The prevalence of sexual abuse of people with ID is higher than in people without ID, and sexually offensive behavior is also identified as a significant problem. Providing professional support in this area means paying attention to the clients' care demands, arising from a professional loving care perspective. Professionals often have not sufficiently developed the acquired expertise for this. The present study's purpose was therefore to develop evidence based training modules to train professionals in the assessment of sexual abuse and disclosure.

**Methods**
The training 'Assessment of sexual abuse' was conducted three times (n = 7; n = 16; n = 15) using a pretest-posttest-design, focusing on knowledge and process insight of professionals required to assess sexual abuse of people with intellectual disabilities .
The training ' Disclosure' was conducted two times (n = 10; n = 11) using a pretest-posttest-design, focusing on knowledge and process insight required to assess a vague spontaneous disclosure of presumable sexual abuse.

**Results**
Participants of the training 'Assessment of sexual trauma and sexual offending' and of the training 'Disclosure' showed significant progress in both knowledge and process insight.

**Conclusions**
Training professionals in assessing sexual abuse and disclosure is an important step in the clarification of these problems, and in turn helps to provide adequate guidelines for treatment.

## *Symposium: Hybrid Spaces of Belonging*

## O – 45

**Social media and people with intellectual disabilities**
Carmit-Noa Shpigelman, Ph.D.[1] and Carol J. Gill, Ph.D.[2]
[1] Department of Community Mental Health, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel
[2] Department of Disability & Human Development, University of Illinois, Chicago, U.S.A.

**Aim**
Social media has considerable potential to empower people with disabilities. However, this issue has received little attention in research. The aim of the study was to "hear the voices", including experiences and difficulties, of people (18 years and older) with intellectual disabilities (ID) who use Facebook, the most popular online social network.

**Method**
We conducted a self-report online survey to reach a substantial pool of people with ID (n=58) who use Facebook. The survey included 49 multiple-choice questions focusing on Facebook use and perceptions, and three open-ended questions about the personal experiences of the respondents and recommendations for future change of Facebook.

**Results**
The majority of the respondents were female (57.9%), 30 years and older (57.9%), and residents of U.S. (84.5%) who have learning disability and/or ADD/ADHD as a secondary disability (51.2%). We found that the respondents with ID visit Facebook at least once a week (67.2%) with no assistance from a caregiver or friend (82.8%), and use it primarily for connecting with people they meet in face-to-face settings (e.g., friends, family members, caregivers) rather than people they meet only online (10.5%). Most of them enjoy using Facebook while at the same time they perceive it as an inaccessible and unsafe environment.

**Conclusions**
The survey revealed the benefits associated with using Facebook by people with ID. The results also revealed some difficulties such as issues of privacy and accessibility. Future development of social networking sites should be accommodated to their needs, including simplified version, voice-control programs and more graphics.

## O – 46

**Inclusion as Heterotopia: Spaces of Encounter Between People With and Without Intellectual Disability**

Herman P. Meininger[1,2]
[1] Willem van den Bergh Chair, VU University, Amsterdam, the Netherlands
[2] 's Heeren Loo, Amersfoort, the Netherlands

**Aim**

The public space to which - in line with common definitions of inclusion - persons with intellectual disability are designated often turns out to be a space of discrimination. Aim of this study is to identify spaces of encounter and belonging.

**Method**

Michel Foucault's concept of *heterotopia* - 'other spaces' – and its subsequent interpretations are used as an analytical tool for evaluating efforts to include persons with intellectual disability in society.

**Results**

In Foucault's work 'space' refers to geographical places and to 'sites' that can be defined by sets of relations. Among these spaces are 'counter-sites' like prisons, hospitals and residential facilities. Though contemporary policies aim at erasure of these 'heterotopia of deviation', the results of these policies of deinstitutionalisation are often disappointing. Recent interpretations of the concept of heterotopia position the 'other places' in the middle of ordinary life as spaces of encounter and dialogue. Characteristics and practical conditions of such spaces of encounter are explored.

**Conclusion**

The analysis opens up a new conceptualisation of inclusion in terms of niches in which encounter and belonging are cultivated and an alternative social ordering can be exercised.

## O – 47

**"Focus on Friendship"; (dialogue) conversations about social relations with secondary schools and their students with autism**

Gigi Dingler, Saskia Buma, Alma Wattimena
Nederlandse Stichting voor het Gehandicapte Kind (NSGK)/ NSGK: a Dutch Organisation for children and young people with disabilities, Amsterdam, the Netherlands

**Aim**

The aim of this project is to put the topic "social relations" on the agenda of (special) secondary schools and their students with autism.

**Methods**

1) Interview
We organize interviews with the schools and ask about their experiences, vision and activities related to social relations.

2) Dialogue sessions and trainings
We offer dialogue sessions about friendship in the classroom. Dialogue is the opposite of a discussion. It's about listening to each other. A dialogue can make students aware of their experiences, desires and their own role. Practicing the skill of listening and meeting each other in a personal way can contribute to the interconnection. Teachers can be trained to guide dialogues themselves.

3) Publicity
Free publicity will help to put "social relations" on the agenda of the schools.

**Results**
At this moment (April 2013) three schools participated in the project and two interviews are planned. School are enthusiastic about the project, but a lot of them are too busy with their daily business to put extra effort on social relations (including the dialogue experience). We expect there will be more space for the project in the next school year (Sept 2013). However, the first teachers who experienced a dialogue session where very positive and the participating students too. They want to repeat the dialogue regularly with their students.

**Conclusion**
It is the intention of NSGK to continue this project for secondary schools focussed on students with different kinds of disabilities. At this moment it's too early to draw conclusions. In October/November we can tell more about NSGK's intends with this project.

## *Symposium:* Belonging 'Inside-Out'

## O – 48

**Friendships: a personal story of formation, loss and maintenance**
Josh McDonagh
Bristol, UK

I am a young man (20 years old) who has cerebral palsy with learning and physical disabilities. I am currently studying a BSc in Architectural Studies at Cardiff University, Wales, United Kingdom.

As a person with physical and learning disabilities being a member of the 'able-bodied' world has been experienced as both enabling and disabling. This has been particularly manifest through the formation, loss and maintenance of friendships. Whilst a mainly positive personal experience will be shared a few unhappy experiences will also be explored through consideration of those friendships:

- which worked/ are working well
- I would have liked to happen yet did not develop
- which I chose to end

Through telling the story of my friendship experiences the influence of assumptions about:

- disability
- the intellect of people with disability
- the capabilities of people with disability

will be considered and challenged. The presentation will be concluded with my views on how positive friendship experiences could be supported and so the social inclusion and psychological well-being of people with disability enhanced.

Relevant imagery will be used to tell my story through a power point supported presentation.

## O – 49

**Hear, look, touch. Stories about self-transforming experiences in proximity of, and encounters with other bodies**
Gustaaf F. Bos
Willem van den Bergh Chair for Social Integration of People with ID, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

**Aim**
The Dutch policy of 'reversed integration' – reshaping (parts of) residential care facilities into neighbourhoods for people with and without intellectual disabilities – aims at stimulating encounters and social relations between stakeholders in safe and structured neighbourhoods. Stakeholder stories are analyzed in an attempt to: 1. gain insight in (their perspectives on) daily interactions in their neighbourhoods, and 2. compare these interactions and perspectives with the aims of policy makers.

**Methods**
Participant observation, interviews, narrative inquiry, data-triangulation (member checks, focus groups, peer reviews (Abma, 1998; Abma, Bos, Meininger, 2011). Each stakeholder's perspective was constructed and discussed on multiple moments, in varying environments, and by different stakeholders – in an attempt to get the most relevant, credible, and recognizable themes. Themes are input for further analysis and discussion.

**Results**
In joining in (and evaluating) daily human interactions, much of our conscious attention is aimed at verbal aspects. Remarkably often, people tend to consider the prospects of inter-neighbour communication as the equivalent of the prospects of sharing spoken language. Extensive bodily participant observation and a lot of doubtful (spoken) conversation outcomes in neighbourhoods for 'reversed integration' stimulated partaking in an ongoing search for meaningful nonverbal interaction alternatives between people with and without intellectual disabilities.

**Preliminary conclusions**
Attention for non-verbal aspects of communication enables people to explore previously unknown possibilities for interaction spaces between self and others. By reflecting on this, people construct new knowledge not only about the other and the self, but also about ways self and other are able to connect ('selfother', Heshusius, 1998).

**References**
Abma, T.A. (1996). *Responsief evalueren: discoursen, controversen en allianties in het postmoderne.* Delft: Eburon.

Abma, T.A., Bos, G.F. & Meininger, H.P. (2011). Perspectieven in dialoog. Responsieve evaluatie van beleid voor mensen met verstandelijke beperkingen en hun omgeving. NTZ. *Nederlands tijdschrift voor de zorg aan mensen met een verstandelijke beperking.* 37(2), 79-87.

Heshusius, L. (1994). Freeing ourselves from objectivity: Managing subjectivity or turning toward a participatory mode of consciousness? *Educational Researcher*, 23(3), 15-22.

## O – 50

**Towards a prototypical conceptual model for the interrelations among disability, belonging and leisure**
Johan Bouwer
NHTV Breda International University of Applied Science, Breda, the Netherlands

**Aim**
Scholars in the field of leisure studies have claimed that their discipline is in a state of crisis due to a failure to accommodate the theoretical and methodological necessities that leisure in the postmodern era demands. In postmodern times leisure should be studied as the key domain in which people find and create meaning by expressing and exploring their freedom But does this apply to people with disabilities as well? It is believed that the field of leisure studies has not been able to develop a coherent body of knowledge on disability and leisure and requires a more inclusive discourse that is informed by new definitions and wider engagement with disability research and disabled people. Could the notion of 'belonging' contribute to this endeavor? Taking up the challenge to engage in developing new inclusive leisure definitions in interaction with disabled people, this paper explores the construction of a prototypical conceptual model that reflects the interrelationships between disability , 'leisure' and 'belonging'.

**Methods**
Qualitative design (N=1), resembling Grounded Theory. A semi-structured interview reflecting the three domains of 'belonging', 'leisure' and 'disability' with Marian, a 56 year old woman with SMA (spinal muscular atrophy), has been digitally recorded. Since the main 'categories' are known, analysis of the transcription started with axial coding, followed by selective coding. The results of this exercise have been discussed in depth with the respondent. New insights have been generated, which in turn, have led to the construction of a first version of the prototypical model. This has also been discussed

with the respondent. Theoretical comparison and further consultations with the respondent have led to saturation and resulted in the model that will be presented.

**Results**
The conceptual model displays three levels of aggregation: (i) a personal-intimate domain (spiritual space) (ii) a social-intimate domain (socializing space) and (iii) a social-contractual domain (public-social space). Level 1 forms the fundamental basis for levels 2 and 3. Three kinds of leisure and three kinds of belonging have been identified, which correspond with these domains. 'Being-leisure' corresponds with 'personal-intimate' belonging (level 1), 'grooming- leisure' corresponds with 'social-intimate' belonging (level 2) and 'participatory' leisure corresponds with 'social-contractual' belonging. The first dichotomy (being-leisure –personal-intimate belonging) is characterized by necessary availability for self resulting in happiness, personal growth and re-creation; the second dichotomy (grooming leisure – social-intimate belonging) by voluntary availability for significant others resulting in happiness, personal growth, re-creation and having fun, and the third dichotomy (participatory leisure – social-contractual belonging) by voluntary availability for social others resulting in personal growth, quality of life, re-creation and social involvement.

**Conclusions**
Disability forms the 'playground' for leisure (i.e. it demarcates/limits leisure possibilities), while leisure forms the fundamental precondition for belonging. Leisure 'space' has been characterized as a spiritual domain, rather than a physical place, and is undergirded by relationality and reciprocity. Belonging seems to be a contributing factor in complementing existing leisure theory – especially with regard to disabled people.

## *Symposium:* Reciprocity and Friendship I

## O – 51

**"Welcome to the machines": autism and the acquisition of tacit knowledge**
Damian E. M. Milton
Autism Centre for Education and Research, the University of Birmingham, Birmingham, UK

Approaches to the ontology of autism have been evolving ever since the phenomenon came into the clinical lexicon, yet the notion of the autistic person somehow being 'machine-like', incapable of true socialisation has remained a repeated descriptive metaphor. This medicalised typology of a separable category of humans, incapable of social reciprocity is criticised within this presentation, by utilising the theoretical framework of tacit knowledge as developed by Collins and Evans (2007). Upon reflection of lived experience and the expressions of others on the autistic spectrum, this framework helped to elucidate issues of social reciprocity between autistic and non-autistic people. Therefore, this presentation will involve utilising concepts such as social parasitism, interactional expertise, and the imitation game, to reflect upon autistic sociality as experienced from the positionality and viewpoint of an autistic academic.

The argument will be made in this presentation through reference to the work of other autistic writers as well as the author's own experiences, that the social parasitism commented upon by Collins and Evans (2007) is never a 'zero-sum' game (truly machine-like), with supposed 'low functioning' autistic people often finding avenues in which to communicate. The counter-examples of those who build a capacity for social communication are not limited to those deemed to have 'mild symptoms', but the vast majority of those on the spectrum. The socialisation process as experienced by the non-autistic person however is contrasted as qualitatively different in terms of how this process is experienced by those on the autism spectrum. Rather than being analogous with machine-like operations however, it is argued here that being autistic represents a diverse and often disparate spectrum of sociality. In keeping with other autistic self-advocates, this presentation will refer to 'autistic people', and 'those who identify as on the autism spectrum', rather than 'people with autism'.

**References**
Collins, H. and Evans, R. (2007) *Rethinking Expertise.* London: University of Chicago Press.

## O – 52

**Givers and receivers: auto-ethnographic stories and self-reflections about life in a Flemish institution for people with an intellectual disability**

Frank A. Renders
Anthropology, Faculty of Social Sciences, KU Leuven, Leuven, Belgium

**Aim**

The process of alienation I experienced in the course of fieldwork as a caregiver in a Flemish institution is described. Alienation is considered as a tool to obtain scientific knowledge and insights. It is a precondition that enables to relate with the strangeness of the other. My research further investigates this claim.

**Methods**

Auto-ethnographic stories and self-reflections are the central building blocks. This resulted in a self-willed style of writing consisting out of a collection of different texts (subjective stories, theoretical considerations, excerpts of files, notes, reports). A connection is sought between the subjective, the cultural and theoretical level. These perspectives together constitute my framework of reference by which I perceive and coherently represent life in the institution.

**Results**

Alienation embraces a double movement: on the one hand it refers to a clash between myself (the researcher) and the other. In the second movement, an intense exchange takes place between myself and the institutional surrounding. This interplay takes place in a space-in-between. Attention is on my performance and the way I understand, interpret and create meaning through a simultaneous internal dialogue. It reveals the reciprocal nature of the concept of belonging.

**Conclusions**

This method is a relevant strategy to portray the process of mental growth of the researcher-caregiver. It also generates an additional perspective about the figure of the resident, namely as a 'giver of knowledge and information'. This requires a redefinition of the traditional understanding of care. People with an intellectual disability can only be depicted as 'givers' only when the caregivers identity themselves as 'receivers'. In the current system of care this perspective is neither a theme nor a practice.

## O – 53

**Unfolding the Proposed World We Can Inhabit Together: 'Belonging' in Art and Theology**

Emmanuel Nathan
Faculty of Theology and Religious Studies, KU Leuven, Leuven, Belgium

**Aim**

To use input from the visual arts in order to come to a theological reflection on the 'art of belonging' as it pertains to disability.

**Methods**

1. Introduction with film fragment, *Gattaca* (1997) and drawing, *Moon Landscape* (Petr Ginz, d. 1944): depict alienation and non-belonging.
2. Main body of paper - Two separate *corpora*: (1) the artwork of young persons with mental and physical disabilities contained in the catalogue *Eine Welt Ohne Mauer* (1999), and (2) Jörg Niederberger's *Apsidengemälde* (2006) in the Dreifaltigkeitskirche (Bern): separately depict the active desire for belonging in a world without walls and mutual indwelling.
3. Hermeneutical/theological framework: *Normativity of the Future* (Bieringer and Elsbernd, 2010), now applied to disability and belonging.

**Result**

The experience of disability, in particular the alienation brought on by exclusion and non-belonging, is a catalyst towards discerning cultural scripts (the visual arts being one of them) that can inspire hermeneutical and theological reflection.

**Conclusion**
The visual art under discussion 'unfolds a proposed world to be inhabited' (Ricoeur 1991: 86) in which there is mutual indwelling and belonging with others.

**References**
Bieringer, Reimund and Elsbernd, Mary (Eds.). *Normativity of the Future: Reading Biblical and Other Authoritative Texts in an Eschatological Perspective*. Annua Nuntia Lovaniensia 61. Leuven: Peeters, 2010.

Herzog, Christiane (Ed.). *Eine Welt ohne Mauer. Bundesweiter Schulmalwettbewerb des Haus am Checkpoint Charlie*. Berlin: Haus am Checkpoint Charlie, 1991.

Ricoeur, Paul. *From Text to Action: Essays in Hermeneutics II*. Evanston, IL: Northwestern University Press, 1991.

## *Symposium:* Reciprocity & Friendship II

## O – 54

**The use of images in supporting dialogue**
Sofie Sergeant[1,2], Saar De Buysere[3]
[1] Disability Studies, UGent, Ghent, Belgium
[2] Vonx, Sint-Amandsberg (Gent), Belgium
[3] Independent artist, Ghent, Belgium

Saar De Buysere and Sofie Sergeant created two image books titled 'Dingske' ('Thingie') and 'Nu en Straks' ('Now and Next´), which comes with a manual and a personal exercise book. It was published in 2010 (Dingske) and 2013 (Nu en straks) by Garant, a Belgian publishing house.

If a work of art, an image, appeals to an observer, he or she will try to become part of it. This sets in motion a whole process, involving all human senses.

When people observe an image, they often start talking about it: they try to convert the sensations they experience by looking at it into words, which will in turn create new sensations. By sharing these words, the observer's perception is influenced once again. Does perception shape these words, or do they shape perception? I'm convinced it works both ways.

*My proposition is that visual materials are essential to communicate successfully with people with intellectual disabilities.*

Therefore we created the picture books 'Dingske' and 'Nu en straks'. This neatly brings us to the three ways of using a picture book:

- You can use the picture book to provide information for someone.
- By using leading questions, you can invite someone to look at the pictures as a means to start a discussion.
- You can let someone watch the pictures without any objectives or 'hidden agenda'. In this case, you are not driven by any specific need for knowledge. In deliberately not digging for information, you often get to discover fascinating stories and reach a better understanding of how this person perceives his or her environment.

In my opinion, the added value of these visual materials consists in:

1. structuring the conversation by providing the participants with something to hold on to
2. stimulating both the caregiver's and his or her conversation partner's capacity to concentrate
3. allowing the conversation partner's agenda to lead the discussion. In discovering their agenda and how they perceive their environment, you can better
    a. inform them
    b. put them at ease
    c. allay their fears

4. providing a means to communicate effectively by picking the conversation partner's preferred 'channel'.

Will everyone be able to benefit from this approach? No, some people simply don't 'get' images and will be better served by applying other methodologies, such as using non-visual forms of sensory perception.

Hence my appeal: please let us use multiple forms of discourse. Let us combine written texts with drawings, photos and other types of illustrations. And, especially when entering into a dialogue with people with intellectual disabilities, let us also involve the other senses: taste, smell, sound and physical touch.

## O – 55

**Belonging through Storysharing®: processes of attunement and reciprocity**

Nicola C.Grove
Openstorytellers Limited, Black Swan Arts, Somerset, UK

**Aim**

Storysharing® (Grove & Harwood, 2013) is a narrative intervention programme designed to enable people with severe communication difficulties and those who support them to recall and co-narrate significant experiences. The aim of the research is to identify some of the mechanisms which contribute to the development of a sense of belonging (Cobigo, 2012) when personal narratives are shared between individuals and within communities.

**Methods**

Two videoed conversations are used to explore the ways in which narrators attune to each other, and respond reciprocally. Close analysis of the group conversation using an ethnopoetic framework (Hymes, 2010) illustrates the ways in which the story is co-constructed, and patterns of listening, initiating and co-narration which link the speakers.

**Results**

Results show intricate reciprocal patterns of intonation, gesture, echoed words and phrases. It is argued that such patterns exemplify the ways in which empathy and mutuality are developed between friends and within communities.

**Conclusion**

Shared narratives offer a context which is supportive of patterns of mutuality which may lead to the development of connections between people, which is one way of describing a sense of belonging.

**References**

Cobigo, V. et. al., (2012) Belonging: what might it mean to belong
*Journal of Intellectual Disability Research*, 56**,** 805.

Grove, N. & Harwood, J. (2013) Storysharing: personal narratives for identity and community. In N. Grove (Ed.) *Using storytelling to support children and adults with special needs*. London: RKP (pp. 102-110).

Hymes, D. (2010) When is oral narrative poetry? Generative form and its pragmatic conditions. *Pragmatics, 8*, 475-500.

## O – 56

**To enable belonging: personal relationships between persons with profound intellectual and multiple disabilities in residential facilities**

Annette A.J. van der Putten[1,2], Aafke Kamstra[1], Carla Vlaskamp[1]
[1] Department of Special Needs Education and Child Care, University of Groningen, Groningen, the Netherlands
[2] 's Heeren Loo Zorggroep, Amersfoort, the Netherlands

**Aim**

For persons with profound intellectual and multiple disabilities (PIMD), number and frequency of non-professional social contacts is very limited, including contact with peers with PIMD. We believe belonging has to start within the small community of the living environment of a person with PIMD, and that especially contact between persons with PIMD should be enabled and stimulated. As people with PIMD need support in every aspect of their daily living, this also applies for enabling personal relationships between them. This is also related to the literal position a person, being confined to a wheelchair and unable to move himself, captures in the room.

**Method**

Fifty people with PIMD (N=50) from different settings participated. To observe and analyze interactions between peers, interactions are related to position: the actual placement of a person in the room. Extension, frequency and content of observable interactions are analyzed using the coding scheme of Nijs.

**Results**

Preliminary results show that people with PIMD are placed in the same position for most of the day, meaning that they are limited in making contact with their peers, and without being given the ability to interact with peers that they favor.

**Conclusion**

Direct support staff becomes aware of the importance of social peer-relationships and the role of position in the process.

## Stream: Inclusive Methods

### *Symposium:* Designing Methods for All

### O – 57

**One for all, all for one – working together for optimal participation of people with intellectual disabilities/Down syndrome. A connection between disability studies and patients participation perspective**

Susan Woelders, Tineke Abma, Frank Renders, Tamara Visser
VU Medical Centre in Amsterdam, Faculty of Medicine, department of Medical Humanities, Amsterdam, the Netherlands

**Aim**

Participation is a very broad concept. In this research we focussed on collective participation, on "having a voice". The first aim was to make an inventory of the needs of people with *intellectual disabilities in order to participate in policy, research or education and how the* environment may be more open and inclusive in order to facilitate this participation.
Secondly, we studied the potential and experienced added value of participation, as experienced by clients as well as their environment (e.g. professionals, caregivers). The project, at last, tries to find solutions and manners in order to extent participation of people with intellectual disabilities.

**Methods**

The study followed a responsive research approach and intersects with inclusive research. The aim of this responsive approach is to increase the personal and mutual understanding of a particular situation by initiating a dialogue on relevant issues with and between stakeholders. It consists of cyclical and iterative phases: information from each phase forms the input for the next phase).
For this research we studied three different settings in which people with an intellectual disability participate in policy making, education and research. We also worked together with research partners with an intellectual disability. These research partners were not involved as a research subject but as initiators, performers, writers, analysts and disseminators of the data. Therefore this process of working together formed the fourth setting of study. (references see list below)

**Results**

Our research shows that people with an intellectual disability are able to participate and have a voice in research, policy and education. Participation leads to empowerment and makes personal development possible. To enable this process it's important to reflect on the way they are invited to have their share and are enabled to have a valuable contribution. Creative methods are needed to let them have a contribution, instead of participation in formal settings. Coaches are also needed to support clients in their process of expressing their voice. Finally we can conclude that time is essential to make participation possible.

**Conclusions**

By working together with people with intellectual disabilities we experienced ourselves what happens when we invite them to participate. Our research also sheds a light on the way we look at participation. People with intellectual disabilities are invited to participate, but we use our own framesworks in which they need to fit. Reflecting on the concept of participation is constantly needed to make their contribution valuable and give them a space to have a say.

**References**

Abma, T.A. (2005). Patient participation in health research: research with and for people with spinal cord Injuries. *Qualitative health research* 2005;15(10):1310-28.

Abma T.A., Widdershoven G.A.M. *Responsieve methodologie. Interactief onderzoek in de praktijk.* Lemma, Den Haag, 2006.

Greene, J., & Abma, T. A. (Eds.). (2001). *Responsive evaluation: New directions for evaluation* (No. 92). San Francisco: Jossey-Bass.

Guba, E.G. & Lincoln, Y.S. (1989). *Fourth generation evaluation.* Newbury Park: Sage.

Abma Tineke A. The Practice and Politics of Responsive Evaluation. *American Journal of evaluation* 2006; 27(1):31-43.

Abma et al. *Onderzoek met en voor mensen met verstandelijke beperkingen.* Vraagsturing wetenschappelijk onderzoek met en voor mensen met een verstandelijke beperking, 2006.

Abma Tineke & Broerse Jacqueline*. Zeggenschap in de wetenschap. Patiëntenparticipatie in theorie en praktijk.* Den Haag, Lemma, 2007.

Abma TA. Nierse CJ, Widdershoven GAM. Patients as Partners in Responsive Research: Methodological Notions for Collaborations in Mixed Research Teams. *Qualitative Health Research* 2009; 19(3): 401-415.

Abma TA., Widderhoven GAM. *Responsieve methodologie. Interactief onderzoek in de praktijk.* Lemma, Den Haag, 2006.

Abma TA & Widderhoven GAM. Sharing stories. Narative and Dialogue in Responsive Nursing evaluation. *Evaluation & the health professions* 2005; 2(1):90-109.

## O – 58

**Individual support planning: perceptions and expectations of people with intellectual disabilities in the Netherlands**

Marjolein A. Herps[1,2], Wil H.E. Buntinx[1], Leopold M.G. Curfs[1]
[1] Governor Kremers Center, Maastricht University, Maastricht, the Netherlands
[2] Vilans, Utrecht, the Netherlands

**Aim**

The dreams, aspirations and needs of a person with intellectual disabilities (ID) should be the starting point of supports from a professional organization. Furthermore, supports should focus on the strengths of a person and should also include the social network of the person. The individual support plan (ISP) is an instrument to describe the supports that are needed. It is an instrument that can be used to enhance self-determination and, if done well, can empower a person with ID. Working with ISP's can also enhance the feeling of belonging, the feeling that the person with ID has an important opinion and is taken serious as experts on their own lives. The current study focuses on the perceptions and experiences of Dutch persons with ID with respect to their involvement in their ISP.

**Methods**

A participatory approach was used in the study as two people with ID were part of the research group. Data were gathered through semi-structured interviews with 61 people with mild to moderate ID. Participants were recruited in 23 Dutch service provider organizations. A systematic qualitative analysis was performed on the interview transcripts.

**Results**

Although persons with ID are present at their ISP meeting, active client involvement in developing, executing and evaluating the ISP is not common practice. Issues of accessibility and lack of control over the process and content of ISP hamper effective involvement of people with ID.

**Conclusions**

The study shows that people with ID do not feel empowered by the process and content of their ISP. The ISP places great emphasis on the problems and disabilities somebody is or has been facing, rather than focusing on their strengths and dreams. There needs to be attention to the facilitation of active involvement of people with ID and the content of an ISP for it to function as a tool for enhancing self-determination and empowerment.

## O – 59

### A self-advocate's right to belong as a form of resistance in higher education and disability studies

Toon Maillard[1,2], Ludo Schoeters[2], Marc Callebaut[2], Didier Peleman[2]
[1] Disability Studies and Inclusive Education, Faculty of Psychology and Educational Sciences, Ghent University, Ghent, Belgium
[2] Our New Future NPO, Ghent, Belgium

**Aim**
A process that started as a small dissertation project, grew into a joint search by three self-advocates and a student on ways for people with a label of intellectual disabilities to participate and belong in higher education and academia, a place ruled by rigid views on intelligence, even in a midst of disability studies scholars.

**Methods**
This project was founded on a – Critical – Disability Studies framework in which one starts from a strengths-based model and a cooperative research approach with self-advocates who identify with the label of intellectual disability. We drew heavily on the existing research on emancipatory action research, self-advocacy and the inclusion paradigm.
We developed a methodological approach in which all co-researchers could share their insights. We started from a classic action research cycle (think-act-reflect-cycle), which though our collaborative efforts evolved into a more complex research cycle in which reflection and interaction between researchers was a key part. We organized visits and interviews with key stakeholders in higher education and academia. Which we structured and analyzed using mind maps and rich pictures, so refining our theoretical and practical concepts.

**Results**
One of the outcomes of this research project was an event in which we shared our narratives, findings, thoughts and questions with key stakeholders, both national and international. It brought together a group of self-advocates, researchers, lecturers, vocational workers, policy makers, students and supporters. The workshop was created and facilitated by a self-advocate and a student, thus creating a place of belonging and participation, as well as resistance within academia and disability studies.

**Conclusions**
Through the co-creation of these projects in which a collaborative research approach and a positive valuing of talent is paramount, we can create spaces of belonging with and for people labeled as having intellectual disabilities within the fortress of academia.

# Stream: Workshops

## *Workshop:* Accessible Society I

## O – 60

**The Power of Valued Social Roles**
Hans Kroon, Wil Molenaar
Perspectief, Utrecht, the Netherlands

Social Role Valorization (SRV) is an effective way to work on inclusion using well grounded scientific theory. This theory was developed by Wolf Wolfensberger (university of Syracuse, New York) at the end of the 20th century. He described in detail all forms of exclusion in society in line with this theoretical foundation and developed insights and practical ways to counter exclusion of vulnerable people in all walks of life. Thinking and acting based on SRV are at the basis of inclusion as well as the principles and articles of the Convention on the Rights of Persons with Disabilities.

In addition to a strong vision on inclusion and insights in mechanisms of exclusion, SRV offers practical ways to people who are marginalized – even the most vulnerable of them – or people who run the risk of marginalization. Important themes are: devaluation and its consequences, power of mindsets and expectations, social valued roles, cultural valued analogue, the conservatism corollary, model coherency. The construct of social roles can be a powerful tool in analyzing and explaining what happens to impaired or otherwise devalued people, for crafting action measures on their behalf and for restructuring human services.

In our workshop we want to explain and illustrate some of the mentioned themes, with exercises/ films/ pictures, in a way that the audience can experience the impact of the value of SRV and what it means to them in their life and work. We show them how everybody can contribute in every day situations to “the art of belonging”.

## *Workshop:* Experiental Knowledge

## O – 61

**Nothing about us without us! How to fulfill participation**
Nancy Lievyns
GRIP vzw, Brussel, Belgium

Our aim is to explore the concept ‘experiential knowledge (EK) and the importance of EK in Disability Studies.The abstract is based on our presentation at the ‘Nothing about us without us! Conference’, Louvain 2009. It was the result of an internal consultation with GRIP volunteers working on EK.

Historically society was built by people without a disability. People without a disability organized research and social work. People with a disability had no voice. And still haven’t one. Nevertheless people with a disability have an interesting view on disability, starting from their experience.
We at GRIP are convinced that it is a human right for people with disabilities to take part at all levels of society. We are all born in the same world. We all have the right to contribute to our world. So it’s our right to claim the recognition of our disability experience a.o. on the field of research and social work. We work hard for more experiential knowledge (EK) in a.o. research and social work.
Before we can use experiential knowledge, it is important to have a unambiguous definition of the concept.
Research is important in the construction of society. It can make all the difference. So we plead for Disability Studies. In Disability Studies people with a disability must be involved. The main question is how to realize participation of people with a disability in research programmes. How can we evolve from a suffering object to a leading subject? What does the input of experiential knowledge mean for research objectivity? And how can we guarantee that everyone can take part? Or can only people with an academic title take part in research? Which competences are needed to put in your disability experience? How can we, as persons with a disability, take leadership in research programmes?

We, as persons with a disability, have a unique disability experience that leads to disability identity and a disability world view. Our perspective is essential if we are to come to a society that respects any form of diversity. That is why we strive for the recognition of experiential knowledge. In dialogue, experiential knowledge and professional expertise reinforce one another. Without a clear framework, experiential knowledge does not have any strength. For everyone to be given the opportunity to use experiential knowledge it is imperative that a number of preconditions are met.

## O – 62

**Experiential knowledge within disability (studies) research**

Jacqueline Kool[1], Jenny Boumans[2], Merel Visse[3]
[1] Disability Studies in Nederland, Amersfoort, the Netherlands
[2] Trimbos Instituut, Utrecht, the Netherlands
[3] VU Metamedica department, Vrije Universiteit, Amsterdam, the Netherlands

**Aim**

Within the field of disability related research, experiential knowledge (EK) or lived experience of persons with disabilities is increasingly valued as part of the research input. But too often it remains undefined what experiential knowledge *is* and how (under what conditions) it relates to other kinds of knowledge in research. In our project we aim to develop a theoretical and conceptual framework on the nature, meaning and the use of EK.
Assuming that 'belonging' from a disability studies perspective *requires* fundamental understanding and deployment of knowledge that is derived from disability experiences within research and practice, we would like to share the results of our project during this conference.

**Methods**

In discussions on the deployment of EK within academic research settings, people with EK and researchers are often regarded as two different groups. Many researchers in the field however also *live* disability experiences everyday. By bringing together a group of researchers in the disability field with this so-called "*double identity*" in expertmeetings, we conceptualised EK through a series of *concept maps*. The outcomes were translated into a questionnaire for persons with a disability involved in research f.i. in patient- and self advocate organisations.
We focussed on four main questions: a. What is EK? b. How does it emerge and develop? c. What is its validity? (in relation to other types of knowledge) d. What does it mean and how does it work? (on subjective and societal level).

**Results**

The preliminary results imply that EK is hard to grasp in a fixid framework. Because the object of knowledge is the *subject itself* (in contrast to 'scientific' knowledge which studies the object of *disability*), the content of the concept is complex, ambiguous and sometimes contradictory. EK nevertheless has a specific meaning for researchers who deal with disability and others they cooperate with. Researchers benefit from this knowledge implicitly and sometimes explicitly to enrich their investigation.

**Conclusions**

EK can be conceptualized from multiple paradigms, and from an insider and outsider perspective, allowing a more dialogical and a more critical approach to coexist.

## *Workshop:* Belonging in Education

## O - 63

**Universal Design for Learning: belonging to education**
Judith Jansen
Expertisecentrum handicap + studie, Utrecht, the Netherlands

Universal Design for Learning (UDL) is quite unknown in The Netherlands. Handicap + studie, the Dutch expert centre for students with a disability, started spreading the idea of UDL in the field of higher education. By thinking in an UDL way, teachers, students and many more are able to provide all inclusive education. In this session we will introduce the concept of UDL and the importance of UDL for (the art of) belonging of students with a disability to higher education.

UDL is based on the principles of Universal Design, the term launched by the architect Ronald L. Mace to describe the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life.

Universal Design for Learning means designing an educational environment in which diversity among students will become the standard. Flexible curricula are fit to meet with limitations and abilities of all students and retrofitting and individual adjustments are seldom necessary. This will meet the needs of the diversity of all students in higher education. While every student differs in the way in which why, how and what he learns.
In this way UDL stimulates the exchange between the personal and social worlds of studying with disability and supports the art of belonging in which “individuals with disabilities find their places in life, without compromising themselves for the purpose of fitting in”.

## O - 64

**Universal Design for Learning: How can we make it everybody’s business?**
Katrien De Munck
Steunpunt Inclusief Hoger Onderwijs (SIHO) / Support Centre for Inclusive Higher Education, Brugge, Belgium

**Aim**
The Support Centre for Inclusive Higher Education (SIHO) supports the Flemish higher education (Belgium) to become inclusive. SIHO is led by the UN-Convention on the Rights of Persons with Disabilities and works from a Disability Studies perspective.
SIHO received quite some questions inspired by medical model thinking. For example faculty asked for manual-like information on how to deal with students with disabilities (how do I deal with students with autism, dyslexia, …?). The aim was to find an appropriate answer to this questions.

**Methods**
Since October 2009 we picked up the work on UDL. Since then we use different means to implement UDL in the Flemish higher education: we give workshops, trainings, conferences, coaching, we have a website on UDL and ICT.
We aim to reach all stakeholders in higher education on the importance of UDL by giving concrete tools and an inspiring framework. Staff involved in teaching can use the material directly. Policy staff gets entrances for implementing UDL at institutional level.

**Results**
We spread the word on UDL constantly and through different media. Staff members of all the higher education institutes in Flanders participated in trainings, workshops, coachings and use the material on our UDL-website.
Trying to get a view on the reach, we see that from May 2012 till May 2013 the UDL-website got 11676 visits. Since October 2009 we organized or participated in 40 events to inform about UDL. Since then more than 130 people get coached on implementing UDL in their work. Next to their own practice, these people influence their colleagues, departments and institutions.

**Conclusions**
Offering UDL as a method to create equal chances, was received very positively. It recognized teaching staff as competent actors in connecting to all students. It showed the key role that teachers can play and made it very accessible for them how to play this key role.
The framework of Universal Design for Learning (UDL) was the perfect answer to these questions. Instead of discussing how to look at disability (medical or social model) it leads people to the educational practice. Every learner is different. It's impossible and not necessary to know everything about disability, but to focus on the learning instead.
UDL fits the disability studies perspective: "It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality" (Shakespeare & Watson, 2001, p.19, as cited in Gabel & Peters, 2004). This multiplicity and the fact that next to UDL individual adjustments will always be needed, makes disability to be an inspiration for accessible and quality education.

**References**
Gabel, S. & S. Peters (2004). Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability & Society*, Vol. 19, No. 6, October 2004. Pp. 585-600.

## *Workshop:* Accessible Society II

## O - 65

**Dialogue workshop "The Art of Belonging"**
Gigi Dingler, Saskia Buma, Alma Wattimena
Nederlandse Stichting voor het Gehandicapte Kind (NSGK)/ NSGK: a Dutch Organisation for children and young people with disabilities, Amsterdam, the Netherlands

During this workshop we will set up a dialogue together about the topic: "The art of belonging". A dialogue is a conversation between two or more people in which you personally speak and adopt an open listening attitude. A dialogue is the opposite of a debate or discussion, it is not to convince, but to share.

Dialogue meetings can be used to raise awareness of yourself as an individual or organization. Dialogues may also be suitable to promote cohesion in a group or team or to resolveconflicts. Dialogue sessions can be fertile during merger talks, are used as team building sessions and cabinet formations. The dialogue method is also valuable for investigating topics as a team, for example during evaluations or policy development processes.

The dialogue method is applied in the NSGK-project Focus on Friendship (see the conference programme of Friday the 1st of November). NSGK brings teenagers with autism in conversation about friendship and trains schoolteachers in hosting dialogues. The dialogue method is also applicable for support groups of patients and parents associations (of children with handicaps).

# Stream: Inclusive Education

## *Symposium:* Belonging through Education I

### O – 66

**Looking through a new lens: educational status quo and the social model of disability**
Artemi I Sakellariadis
Centre for Studies on Inclusive Education, Bristol, UK

**Aim**
This presentation seeks to explore underlying assumptions in conventional ways of understanding special education. It is often assumed that disabled children should be educated in special schools. This habit, which many nowadays see as a breach of children's rights, was established in an era when disabled people were thought to have no place in mainstream society. Today full access to mainstream life and institutions is enshrined in law, but education has yet to respond to the criticism that mainstream school structures, more than pupils' impairments, constitute barriers to learning and participation.

**Methods**
This paper explores conventional educational practices and disabled children's sense of belonging to their local community, from the standpoint of the social model of disability. During the presentation, a collection of brief narratives will be juxtaposed with opportunities for comment or reflection.

**Results**
Not applicable.

**Conclusions**
It is my aim to invite delegates to explore their own standpoints from a range of perspectives; this could potentially lead some delegates to new conclusions. Articulating my own conclusions in advance would undermine this process.

### O – 67

**Preschool children's attitude-perception towards children with disability**
Dana Roth, Heli Perez
Research and Evaluation department, Beit Issie Shapiro, Ra'anana, Israel

**Aim**
Including children with disabilities in the regular school system in Israel is the law since 1988. In 2007 Israel signed the UN convention on disability rights which was ratified in September 2012. Thus, inclusion needs to be implemented by "default", all kids should attend the same schools, yet this is only partially practiced. For inclusion to be successful, a central issue which has to be addressed is the attitude of children towards their peers with disability, which should be assessed and intervened if necessary.

**Methods**
Preschool children aged 5-6.5 years old (N=100) were "interviewed" via a measure which was developed (like a game) to assess kindergartners attitudes-perceptions towards children with disability. The children were selected from 10 different kindergartens, after their parents' signed an agreement for their participation. Each child was individually "interviewed" for about 15-20 minutes. The measure addresses issues in the cognitive, emotional and behavioral areas.

**Results**
Preliminary findings (N= 100) will be reported which are presenting some concerning data on young children's perceptions-attitude- understanding of disability. The findings suggest the importance of early education to change and establish positive attitudes. Analyses will address gender, age, and familiarization (personally) with disability.

**Conclusions**
Children as young as preschoolers have definite attitudes-perceptions regarding disabilities. Some of them are disturbing which can be a strong basis for developing negative attitudes. Their responses and explanations reveal thought, rationale, logic which is based on lack of knowledge and information which can be addressed and should be by the education systems as early as possible.

## O – 68

**Can disabled children in the Netherlands get access to (mainstream) education by litigation in international courts and in this way to the status of belonging?**
Thiandi Grooff
Independent author and student at Amsterdam University College, social sciences, Amsterdam, the Netherlands

**Aim**
The right to education is taken for granted in The Netherlands. But access to education can be denied in the Netherlands. The Dutch Council of State decided twice, in 1999 and in 2005, in my case that access to school can be denied not only on pedagogic-didactic grounds but also on organizational ground[1]. In 2011 16641 children in the compulsory school age did not attend school. 4000 children in the compulsory school age spend their days in a daycare centre because they are labeled as “non learnable” , vaguely defined in article 5 of Dutch Educational law.
In my presentation I want to address 3 questions:
1) Why is it wrong to exclude certain children from education?
2) Is it possible for parents to go to international courts to get access to education and in this way to the status of belonging?
3) Is it possible to get access to mainstream education via these international courts and thus to the status of belonging to mainstream society ?

**Methods**
I analyzed the various international conventions and charters on the right to education and the caseloads of their courts.

**Results**
In the HUDOC database for caseload of the ECHR on this subject I found three cases in which violation of the access to education has been stated by the ECHR. There are no cases were the access to education has been discussed for a person in the compulsory school age with identified disabilities. In one case (Cosans and Campbell versus UK) the ECHR was very adamant in valuating the right to education of the student over the right of schools to require certain conditions. In the 2 other cases it was clear that refusing a specific ethnic group to mainstream schools was severely condemned by the ECHR referring to free access to mainstream education for everyone.
A more important fact though has been found: the reality that it is very difficult to get your case admitted, as long as it is politically too sensitive for the ECHR to rule very differently from the politics in the country of the applicant. Then the ECHR would risk a more negative attitude of that country towards the ECHR.
In the case load of the European Committee of Social Rights I found a useful case : Autism-Europe versus France in which the European Committee stated that the State (France) had a positive obligation, as postulated in the European Convention to provide sufficient support for pupils with autism to profit from Education.
Reading the Dutch court cases, one realizes that many people, even, or especially, the intellectual ones, agree with the current policy to exclude certain children from human rights

**Conclusions**
1. It is not ethical to exclude certain children from human rights as the right to education. Even as they apparently never will profit from education.

[1] ABRvS 200505727/1 and H01.98.1591

2. If a child, whose access to school has been denied by the Dutch Courts, will apply at the ECHR, the obstacle of admission will be harder to take than winning the case. Once admitted the chance to win is big, with the Cosans case offering important jurisprudence and with the growing requests for positive obligations for the states as postulated in the European Convention of Human Rights, the European Social Charter of the Council of Europe, the European Union Charter of Fundamental Rights and Freedoms, the UN International Convention of the Rights of Children and the Un International Convention of the Rights of Persons with Disabilities

3. From the caseload of the ECHR there is no jurisprudence for the right to mainstream education for children with disabilities, although it is strongly recommended by the UN ICRPD on ethical grounds and supported by growing scientific evidence as to the academic benefits for both students and society.

## *Symposium:* Belonging through Education II

## O – 69

**"I just want them to see me as Lisa, not as the one with a disability!"**
**How students with a disability try to find their way in a Faculty of Medicine & Health Sciences**
Stephanie Claus[1], Elisabeth De Schauwer[1], Geert Van Hove[1], Karen Leyman[2], Meggie Verstichele[2], Lies Tijtgat[3], Anselme Derese[4]
[1] Ghent University, Disability Studies and Inclusive Education, Ghent, Belgium
[2] Support Center for Inclusive Higher Education (SIHO), Brugge, Belgium
[3] Ghent University, University Centre for Vocational Training and Coaching, Ghent, Belgium
[4] Ghent University, Centre for Education Development, Faculty of Medicine and Health Sciences, Ghent, Belgium

**Aim**
The goal of this research is to look at the strategies students of a Faculty of Medicine and Health Sciences use to find their place in the dominant discourses of the university, in which emphasis lies on achievements/performances and where a medical and market discourse still predominate.

**Methods**
18 interviews with students and graduates with a disability from the Faculty of Medicine and Health Sciences (Ghent University) were analyzed based on the question "How do students with a disability consider themselves and their disability?". Key themes unraveled themselves and it was apparent that students use different kind of strategies to cope with the demanding climate of the university. This insight led the researcher to review literature and brought her to Foucault's concept of transgression.

**Results**
Through Foucaults' concept of transgression we elaborate five movements students with a disability make to maintain themselves at the university: concealing difference, struggling with normality, showing one's capabilities, using a label as a beacon and repeating forms of exclusion.

**Conclusions**
Most of these movements can be seen as a way of transgressing 'the disabled identity', in order to get recognition as a student and as a person with capacities.These movements reject the notion of persons with a disability as passive, fixed objects, rather students are active subjects that, as part as a continuous process of becoming, choose over and over again to move in/out/in between (dis)ability and (ab)normality.

## O – 70

**Educating health care students to listen to the insider perspective of people with disabilities**

Inge Bramsen[1], Mieke Cardol[1,2],
[1] Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands
[2] Netherlands Institute for Health Services Research, Utrecht, The Netherlands

**Aim**
People with intellectual disabilities differ in certain aspects from other people and may therefore experience stigma. This may influence their sense of belonging in the community. This study examined how to train health care students to take into account the insider perspective of their future clients.

**Methods**
Four students examined the images of people with intellectual disability among students in the allied health professions and people with intellectual disability (PwID) themselves. They interviewed each other, six other health care students and six people with intellectual disabilities. The interviews were transcribed and analyzed using a word-processing program.

**Results**
The interviews revealed several themes relevant for the sense of belonging of PwID and the students themselves. “Unknown, unloved” appeared as an important theme, while learning to know people with intellectual disabilities made that they were seen as individuals “that you cannot lump together”. An additional theme centered on “becoming a professional” showing how students developed a sense of belonging to their future professional group. Listening to the insider perspective revealed a shift towards issues relevant for daily life with ID. While listening to the insider perspective, students tended to avoid the painful side of the stories told.

**Conclusions**
Educating students to take into account the insider perspective of people with disabilities requires a dual focus on issues relevant to care and to daily life with a disability. While becoming a professional, students need to learn how to deal with painful emotions of their future clients. Educating students to listen without prejudice to the stories of their future clients also requires that they explore their own experiences, images and values regarding disability.

## O – 71

**From text to texture**
***Count me in*, a curriculum for educating the excluded**

Philomene op ’t Hof, Ariene van Westen
Space Station, Goes, the Netherlands

**Aim**
The purpose of the Space station project *Count me in* was to develop a mainstream curriculum suitable for new learners , mature students with intensive support needs. The curriculum aims to educate, to enhance, to include. And, above all to access and occupy those shared spaces of interest and excitement often beyond the reach of sheltered programmes.

**Methods**
The findings are based on practical classroom insights, negotiations, experiments and evaluations. To develop the curriculum, the Space Station crew organized over 60 drama workshops in a mainstream educational setting.

**Results**
During the International Disability Conference, Space Station will offer an oral presentation, augmented by extensive documentation, of the results of the project. The final curriculum promises a new stage of development and enhanced performance for mature students with a profound disability.

**Conclusions**

The new curriculum shows *how* you can teach mature students with a profound disability in a mainstream location, how you can click into the old Latin idea of educating: education as *educare*, leading forth, taking you where you're at and moving one step forward. Education is not about where you start from or how far behind you are. It's as much about the length and quality of the journey. For the students it can be a wild and exciting journey, enriching their lives and offering them undreamt of opportunities to make their contribution to their community. Without major volunteer input and a high level of corporate support, educational projects of this intensity are unviable.

# Stream: Public Policy & Rights

## *Symposium:* Social Network & Public Policy

## O – 72

**Financial incentives for independent living**
Harrie van Haaster
IGPB, Amsterdam, the Netherlands

**Aim**
In Dutch policy development for healthcare a strong emphasis is made on market forces. Health care is seen as a market. Users of healthcare hardly have a market position. The only choices they can make for themselves and which are supported by laws, are the free choice of providers and the free choice of insurance(company). Other laws, like those on healthcare decisions (WGBO) give users a right to refuse a proposal.
I want to defend a stronger position of users on the market by giving them much more possibilities to chose and decide.

**Methods**
A research project was done as part of a ZonMW disability studies program and was completed in 2012. Our research project was done with 59 respondents who have a personal budget to buy care and assistance for themselves. Qualitative interviews were done about what kind of care they buy, what kind of choices they make and how they want the care to be performed. Also family members and caregivers were interviewed. The interviews were analysed with methods of discourse analysis and narrative analysis.

**Results**
Our research shows that users make decisions about 1) Who they prefer to give assistance, 2) When: during which part of the day they need it, 3) Where, the place of delivering assistance, 4) What should be done, 5) How it should be done, 6) How much assistance they need, and 7) Why they want certain assistance. In the process of delivering and accepting assistance, users are constantly fine tuning with the persons giving the assistance. he process both leads to empowerment and improved quality of existence.

**Conclusions**
The user is much more able than presumed in policy developments to act in an economically interesting way: When he knows what he pays, he has a choice to go for a more cheap choice. When he is economic he is able to save something for worse times or spare money for other things. Most of the times users do not want too much assistance or care. Less is often better. Often times users do not choose professionals as assistants. They prefer relatives or neighbours because these are more flexible and offer more social contact.
In these times of sky-high rising costs for healthcare and cuts on the budgets for healthcare, users are asked again and again to take their responsibility. Many users want to and can take this responsibility, but this responsibility must be triggered by financial incentives for private management and independent living.

## O – 73

**Needs and Challenges of Care Givers of Adolescents with Developmental Disabilities in Georgia**
Tamar Makharadze, Anastasia Kitiashvili
Faculty of Social and Political Sciences, Ivane Javakhishvili Tbilisi State University, Tbilisi, Georgia

**Aim**
There are no social services supporting care-givers of persons with developmental disabilities (DD) in Georgia. The study explored the most urgent and unmet needs of families and care-givers of adolescents with DD in Georgia.

**Methods**
The research data were collected via qualitative and quantitative research methods: Seven focus group sessions were carried out with the main care-givers of adolescents with developmental disabilities in the capital city and east & west regions of the country. 28 in-depth interviews were conducted with the key informants (field experts, representatives of international organizations, state agencies and local NGOs) throughout the country. 100 main care-givers of adolescents with disabilities were surveyed on different topics related to their everyday problems and challenges.

**Results**
The research results showed that economic and emotional burden of families with children and adolescents with DD is high. The main care-givers (mostly mothers) have no possibility to be employed as they have to take care over their children with disabilities during the whole day. This situation causes strong emotional burnout of care-givers; their emotional distress is aggravated with social isolation – families with a member with DD experience stigma from society. Family members and close relatives are the main social network of care givers of adolescents with DD. The situation is more severe for single parents of children with DD.

**Conclusion**
There is an urgent need to develop social services supporting the main care-givers of adolescents with DD in Georgia. Among the most required services are psychological consultations, respite care and parents' clubs.

## O – 74

**Historicizing the art of belonging. Disability, activism and social science in the United Kingdom and the Netherlands since the 1960s**
Paul W. van Trigt
History Department, VU University Amsterdam, Amsterdam, the Netherlands

**Aim**
An important way to practice the art of belonging is to form disability groups. Firstly, because belonging is always part of the formation of groups. Secondly, when groups strive for emancipation, they often strive for belonging to another group e.g. 'normal' citizens, or acceptation by the majority group. In this respect, there are striking differences in the way people with disabilities from different countries practice the art of belonging in the formation of disability groups, which raises the question how the formation of disability groups is determined by national contexts.

**Methods**
In my paper I will answer this question by a historical comparison of disability groups in the United Kingdom and the Netherlands.
I will historicize concepts like the 'social model', 'new social movements' and 'human rights' such as used in the Anglo-Saxon context. Instead of using these concepts for my analysis I investigate how and why these concepts were used (or not) in the formation of disability groups.

**Results**
By historicizing concepts and taking into account national contexts my paper will lead to a better understanding of (the history) of disability groups and the contextual dimensions of the art of belonging. The differences between disability groups in the United Kingdom and the Netherlands are explained by differences in welfare state arrangements and political culture.

**Conclusions**
In my paper I will argue we need a new approach to study disability groups beyond the Anglo-Saxon perspective on disability groups, as is often dominant in the field of Disability Studies/ History, because we can not really understand disability groups in other spatial contexts as we see them as lagging behind exemplary groups in Anglo-Saxon countries.

## *Symposium:* The Rights of Belonging

## O – 75

**French Deafs during the 1900's period : a fight for equality**

Yann Cantin
Ecole des Hautes Etudes en Sciences Sociales/Centre de Recherches Historiques, Paris, France

**Aim**

The deaf's situation had changed since 1880, with the banishment of the sign language in the deaf french schools. So, this change was important, not only on education level, but social and life levels too.
So, one detail is important: evolutions of discourses on deaf place in the society. Deaf people educated before 1880's claim the equality, not social favor, and so fight against the social injustices on deafs. And, when french government propose to reduce taxs for deafs, to help them. They rejected it for a reason : «We're like other people, we want just equality!».
But, after the World War I, discourses changed. More and more deafs admit the physical inequality.

**Methods**

Research is based on deafs discourses published in newspapers and books like *Gazette des Sourds-Muets, Journal des Sourds-Muets, Revue des Sourds-Muets, la France Silencieuse...* And, based too on deaf witness about the deaf situation and relation with the french society.

**Results**

A possible response: discourses in the deafs schools claim the inequality for deafs, if they don't talk. And the extinction of deaf teachers, social models for youngest geneations... These discourses where vehiculed by teachers of these schools, and the medical view on deafness.

So, the influence of these discourses, and the extinction of deaf teachers had impacted the deaf community on two principal ways: society place and vision on the deafs.

**Conclusions**

The Impact of educational reform in 1880 is important, not only on educational level, but in social place too. Now, in the 21th century, the influence exists again.

## O - 76

**Self-determination and participation – implementing qualitative aspects of Swedish legislation on disability**

Petra Björne
Research and Development Unit, City Executive Office, City of Malmö, Malmö, Sweden

**Aim**

The Swedish legislation and policies on disability have clear qualitative aims, promoting self-determination and participation, important aspects of QoL. This study investigates how staff in a group home discuss and implement the qualitative aims of the legislation. The point of time chosen, while opening the group home, allowed observing the process of supporting service users to transition into a new home.

**Methods**

Interviews were conducted with the whole group as well as individually. The first group interview was held before the group home was opened. Two further interviews were held on two more occasions after opening. Staff wrote down individual reflections, before opening the group home, and before the last interview.

**Results**
The staff group found it easy to reflect upon the qualitative aims of the Swedish legislation on disability. These reflections changed before and after meeting the service users. Before, service users were included in a terminology of "we", with the implicit assumption that staff preferences coincided with service user preferences. In the following interviews the concepts were far more problematic, even challenged, especially that of self-determination. The terminology developed into one of "they".

**Conclusions**
Transition poses a major challenge to staff in maintaining the intentions of supporting self-determination and inclusion with the goal of QoL. Care staff must be supported in applying qualitative concepts of legislation and policies in a complex context of service users, disability, methods, and quality of life. A multidisciplinary model for implementing self-determination and inclusion while opening a group home will be presented.

## O – 77

**Large Scale Listening: Monitoring the implementation of the UN CRPD in the Netherlands**
Agnes C. van Wijnen
Coalition for Inclusion (CVI), Utrecht, the Netherlands

**Aim**
In the Netherlands the ratification of the UN Convention on the rights of persons with Disabilities (CRPD) has been promised by the current administration, the implementation process is being prepared. The Coalition for Inclusion, a Dutch networkorganisation of people and organizations campaigning for human rights and inclusion of people with disabilities in all areas of life, developed therefor "Treaty around the corner".
The aim of the project is twofold:

1. Awareness raising on the content and significance of the CRPD amongst stakeholders, and preparing local action plans.
2. Developing a research instrument for monitoring the implementation of the CRPD on a local and national level. CVI intends to use the output of the monitoring as input for alternative reports on the Netherlands to the UN-CRPD Committee, and as input for parties involved in local implementation.

We will focus on the background, the functioning, and the results of the LSL monitoring in the pilot.

**Methods**
To monitor the implementation of this human rights treaty there are several options of what to measure and how. Basic choice here is to measure the implementation progress as perceived by the main stakeholders, people with disabilities, their families and their fellow citizens. The method we use is Large Scale Listening (LSL). This method is used on several continents with a diversity of topics.

**Results**
The "VN Vertelpunt", the digital monitoring instrument is finished and working in a pilot version via the CVI website www.vnverdragwaarmaken.nl. In *VN Vertelpunt*, people tell their experiences in daily life concerning disability and society, about inclusion and exclusion. After sharing their experience they answer questions such as where it happened, if it was about autonomy, education, work or something else and whether it was a positive or negative experience. People also rate what effect the case had on their lives. So far people have included more than 150 experiences, positive and negative on all kinds of subjects from a variety of people.

**Conclusions**
Our conclusions with respect to the effectiveness of this instrument for the purpose of monitoring the implementation of the CRPD are that VN Vertelpunt certainly has the potential to monitor local and national implementation given that the number of entries grows. It collects stories from a large variety of people involved, from all over the country with and without disabilities on both positive (inclusion) and negative (exclusion and discrimination) experiences. The VN-Vertelpunt doesn't measure the investments nor the output of implementation but the impact that the level of implementation has in the lives of people.

# Stream: Participation

## *Symposium:* Participation: Belonging Together

## O - 78

**Participation in terms of belonging to this AND that**

Mieke Cardol[1,2]
[1] Rotterdam University of Applied Sciences, Rotterdam, the Netherlands
[2] NIVEL (Netherlands institute for health services research), Utrecht, the Netherlands

**Aim**

Participation in society is often associated with activities (doing) and a distinction between two groups: participants and nonparticipants. The late Gilles Deleuze was interested in the idea of becoming and in a way of thinking that does not separate into categories. The aim of this paper is to explore the insights of Deleuze related to the participation of five people with an intellectual disability and visual impairment.

**Method**

Participatory observation in the homes and workplaces of the respondents.

**Results**

The respondents seem to participate in the small world of a care institution, with special care and adaptations. Using the insights of Deleuze, it becomes clear that they are also involved in activities 'in between'. Charley for example experiences an afternoon of pleasure with a friend who has a guide dog for the blind, when they secretly travel to another town. Albert dreams of studying theology; he weekly visits a bible course. Charley and Albert break open the known order and create new ways of being. This is not easy one person has difficulty realizing her dreams.

**Conclusions**

Deleuzes' theory helps to look at the participation of people with disabilities from a dynamic viewpoint and in the light of possibilities instead of from the static viewpoint of disabilities. Their participation is as complex as others' and includes activities that go beyond the categories of participants and nonparticipants. Safe and smooth places help people to become. Becoming in fact is being this AND that. Discontinuity and indefiniteness are characteristics of becoming.

## O - 79

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

Lien Claes, Geert Van Hove
Disability Studies and Inclusive Education, Faculty of Psychology and Educational Sciences, Ghent University, Ghent, Belgium

**Aim**

This doctoral research project investigates life trajectories of people with intellectual disabilities and additional mental health problems in Flanders (Dutch speaking part of Belgium). Their complex support questions turn out to be precursors of endless trajectories in landscapes of care and support. Current research is primarily conducted from an individualistic, medical-psychiatric discourse, focusing on problems and treatment. In contrast, I am more fascinated by the life (hi)stories of people and by their experiences and meanings of particular spaces and places.

**Methods**

The life trajectories of people with intellectual disabilities and mental health problems are studied from a cross-fertilization of the theoretical perspectives Disability Studies and Social/Human Geography. In particular, three life trajectories are reconstructed through intense encounters with people themselves and with people in their natural and professional network, in which multiple research methods are adopted. Pictures appear as a very useful entrance to elicit memories and connected stories and emotions and serve as a communication medium, by which pictures perform the voice of the

photographer. Researcher and research subject also go back to important places and spaces (i.e. former places of residence) and meet people who were important in this places and spaces.

**Results**
This paper explores spaces of belonging, bridging and bonding in the narratives and trajectories of people with intellectual disability. It also tries to capture the way in which place and space can 'other' and 'disable' people. Ass well struggles for space and territoriality and mobility as a form of resistance are investigated.

**Conclusions**
People with intellectual disabilities and additional mental health problems are falling between the two stools of the categorically organized and functioning support systems in Flanders. Illustrative are the endless trajectories between the support system for people with disabilities and the mental health care system. These spaces are often associated with experiences of othering, separation and exclusion. An individualistic, medical-psychiatric discourse is primarily adopted.
Furthermore, but often more peripherally, spaces of belonging and inclusion (for example: a place called 'home', working at the farm, the prolonged relation with former friends and family members) are mentioned. Obviously, also the relational, cooperative way in which this research is carried out, turns out to create spaces of belonging, bridging and bonding. We therefore put forward our relational conceptualization of disability studies, in which pedagogical encounters (see Davies & Gannon, 2009) are central, as crucial in both practice as research.

**References**
Davies, B. & Gannon, S. (2009). *Pedagogical encounters.* New York: Peter Lang Publishing Inc.

## O – 80

**Being there: Social Participation through the eyes of People with Aphasia**
Ruth Dalemans[1], L. de Witte[2], D. Wade[3], W. van den Heuvel[4]
[1] Centre of expertise Autonomy and Participation, Faculty of Health and Technique, Zuyd University of Applied sciences, Heerlen, the Netherlands
[2] Zuyd University of Applied sciences, Heerlen, the Netherlands
[3] Oxford Centre of Enablement, Oxford, UK
[4] Maastricht University, Maastricht, the Netherlands

**Aim**
To explore how people with aphasia perceive participation in society and investigate influencing factors.

**Methods**
In this qualitative study 13 persons with aphasia and 12 central caregivers kept a pre-structured diary, followed by a semi-structured interview. Diaries and interviews were transcribed verbatim and analysed by two researchers independently. Plausibility of the analyses was discussed with a third independent senior-researcher. In a focus group interview the results were discussed with the participants (member-check).

**Results**
The main theme was `being there`: People with aphasia feel isolated but want to feel engaged, feel burdensome and wish to function in an ordinary way. Extracting information is difficult but they want to know what is going on. Often they are not able to work and they wish to contribute to the community in other ways. Although they often feel stigmatised, they wish to be respected. `Being there` was influenced by several factors; personal factors (motivation, physical and psychological condition and communication skills), social factors (the role of the central caregiver and characteristics of the communication partner(s), namely willingness, skills and knowledge) and environmental factors (quietness and familiarity of the place in which the person with aphasia live).

**Conclusions**
Social participation is a theoretical concept that people with aphasia do not use. Instead people speak in terms of engagement, involvement, having a feeling of belonging defined as ` being there`. People with aphasia describe the degree of engagement in social activities as more important than the quantity of performing activities.

## *Symposium:* Belonging: Identity & Empowerment

### O - 81

**The relation between loneliness and social participation of people with moderate or severe physical disability**
Tineke M Meulenkamp[1], M Cardol[1,2]
[1] NIVEL - Netherlands institute for health services research, Utrecht, the Netherlands
[2] Expertise Center Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands

**Aim**
People with moderate or severe physical disability participate less in society than people with mild/no disability. Having a chronic disability is also identified as a risk factor for loneliness. The purpose of this study is to explore the relation between loneliness and social participation, focusing on a) degree of loneliness and participation, b) strength of the relation, c) interplay with other factors like social network and internet use.

**Methods**
A sample of 1477 people with moderate or severe physical disability, all member of The National Panel of people with Chronic illness or Disability. Loneliness was measured by the Loneliness Scale. The following indicators for social participation were used; volunteer work, doing leisure activities, meeting friends.

**Results**
Preliminary results show that about 25% felt (very) severe lonely, less than one third did not feel lonely. More than 20% of the people did volunteer work, almost half of them did club activities monthly. More than half of the people had contact with 2-5 family members or friends at least once every two weeks, almost 10% had contact with 0-1 person. More than one third had contact with family or friends at least once a week using the internet.
Final results on the relation between these factors will be presented at the Disability Studies Conference.

**Conclusion**
There is a great diversity in the extent to which people with disabilities feel lonely and participate in society. Conclusions on the relation between loneliness and social participation, will be presented at the Conference.

### O - 82

**Peer Support as a tool for belonging**
Juultje Holla, Mario Nossin
Perspectief, Utrecht, the Netherlands

**Aim**
To develop training opportunities for people with intellectual disabilities to become peer supporters. As part of a European project of Inclusion Europe called TOPSIDE, Stichting Perspectief and the Landelijke Federatie Belangenbehartiging (LFB) have developed training opportunities for people with intellectual disabilities, enabling them to support others who experience similar life situations. Peer supporters can be examples to others. After the training people with learning disabilities can support others to have a greater sense of belonging, to be stronger and to have a say in their own life's choices. The training has a focus on inclusion, having your own say and valued social roles.

**Method**
The training is accessible for up to 8 people with intellectual disabilities at a time. We have based the training on Tony Booth's *Index for Inclusion*. We have used life topics, such as friends, home, leisure, and work to explain concepts such as inclusion, valued social roles and person centered thinking. Each of the 8 days in the training relates to one topic. Around these topics we have created exercises to teach skills people need to become good peer supporters. Furthermore, we use examples of other people to show belonging and how life can be for people with intellectual disabilities.

**Results**
Peer supporters leave the training with more courage and self belief, with skills to support others in their unique life situations and with an understanding of the importance of belonging. They also leave with a portfolio, a file of good examples that can be used, and a toolbox with posters and questions they can use to get to know and support others.

**Conclusions**
People with intellectual disabilities, given the right type of training, are very capable of learning the skills needed to become good peer supporters, to support other people with intellectual disabilities with their own experience.

**References**
Tony Booth and Mel Ainscow (2002), *Index for Inclusion*, CSIE Ld, Bristol, Revised edition.

Wolfensberger, W. (1998). *A Brief Introduction to Social Role Valorization. A higher-order concept for addressing the plight of societally devalued people, and for structuring human services.* Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agentry (Syracuse University).

Michael Smull, (2011) in *Conversations on Citizenship and Person Centred Work* (Eds John O'Brien and Carol Blessing), Inclusion Press, Vol III pp45-55.

(The theories underpinning our training are many. These publications just give an idea of what is behind this training.)

## O - 83

**"Yes, I can!" The art of social participation of young adults with visual impairments**
Sabina Kef, Karen Sleurink
Clinical Child and Family Studies, Faculty of Psychology and Education, VU University, Amsterdam, the Netherlands

**Aim**
Social participation is challenging for people with Visual Impairments (VI). It is important to realize that social participation is an interplay between person and environment, possibilities and obstacles. In order to improve social participation of persons with VI, data of our national longitudinal study were used to investigate 1) the extent of social participation, 2) the interrelationship between the participation areas and psychosocial characteristics and 3) pathways to successful/non-succesful social participation.

**Methods**
Approximately 300 adolescents and young adults with VI were interviewed in three waves (1997, 2005 and 2010), using a Computer Assisted Telephone Interview. Open-ended questions and (valid and reliable) questionnaires were used to measure participation in three domains of participation: education/work, relationships and leisure activities. Furthermore psychosocial characteristics (i.e. autonomy, stigmatization, well-being) were measured.

**Results**
The results showed that most young people with VI find their way in education and a large group of them had (part-time) jobs. However, they encounter problems in leisure activities and relationships, concerning dating experiences, network size, sexual experiences, mobility and amount of peer-activities. These problems are negatively related to psychosocial characteristics like self-esteem, acceptance of impairment and loneliness.

**Conclusions**

Social participation seems to be an interplay between personal and environmental characteristics. Furthermore, social participation does not imply the same for every young person with VI. Concerning leisure activities and relationships, it seems that young persons with VI are not able to reach their wanted participation, so social participation has to be learned. Therefore, it is more than a right, it is an art!

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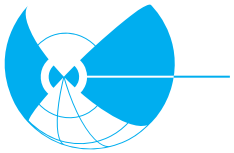
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