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Introduction/Welcome

Welcome to Amsterdam! We meet here for the 3rd International Disability Studies Conference that highlights the theme ‘The art of belonging’.

The theme is reflected in this conference in several ways:

Space for experience
Disability Studies aims to give voice to stories based on lived experience. **Personal experience** is placed in the spotlight, and in this conference we have the chance to exchange knowledge in several ways: by use of words, images, film, theatre, music, … This way, also stories that in a more traditional manner won’t be presented at conferences, will come to light.

A welcoming place
The conference focusses on ‘The art of belonging’: Everyone matters, everyone is welcome. Everyone is valued, originality and talents are seen and appreciated. We aim to contrast inequality, exclusion and stigma that we experience worldwide.

Support for everyone
We want to practice what we preach! Therefore, we aim for accessibility. With a support bar we will organise support for everyone that wishes or requires this. There are sign language interpreters and writing interpreters available, guidance assistants and resting places,… People who don’t speak English, can count on our translators and whisper interpreters. There are workshops in easy language and creative workshops inspiring people to learn by different means than verbal language.

Conference book
We created a conference book with space for your own thoughts, words and drawings. In our conference book we have marked the workshops which are accessible for a broader audience, also for people who do not speak or understand English. We have marked them with an icon and with the NL symbol. The more academic workshops and lectures do not have an icon or a translation in the book. If you need help to go through the conference book and make your decisions, please feel free to ask our help at the support bar.

If you need a translation or other support to enjoy the more academic workshops, please let us know.

We all learn in a different way
We are all different. We all communicate and learn in a different way. Our congress offers a diverse colourful pallette of oral and poster presentations, play, music, dance, active workshops and in-depth academic lectures.
Also, we organise a drawing lab, stand-up comedy, space for ‘chilling’ and resting, good food, drinks and opportunities to meet and exchange.
In the congress book you will find an overview in word and image.
We will try our best in making this congress as accessible as possible. However, chances are that we forgot some minor things. What works for one person, might not necessarily work for everyone. We will need to help and support each other in order to give everyone the opportunity to learn. All of this in order to meet new people, come to new ideas and insights and inspire each other.

A special thank you to all of the contributing authors of the abstracts in this book, our many volunteers, colleagues and our funding partners.

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

On behalf of the organizing committee,

Alice Schippers,
Chair

Inleiding / Welkom

Welkom in Amsterdam! We ontmoeten elkaar hier voor het 3e Disability Studies Congres met als thema: ‘The Art of Belonging’.
Op verschillende manieren willen wij betekenis geven aan deze titel:

Ruimte voor ervaringsdeskundigheid
Disability Studies wil stem geven aan ervaringsgerichte verhalen. **De persoonlijke ervaring** wordt op de voorgrond geplaatst in dit congres. We geven mensen de kans om hun ervaring uit te drukken via het woord, het beeld, film, theater, muziek, ... Zo komen ook verhalen aan het licht die anders, op een meer traditionele manier van presenteren, niet zouden worden verteld op conferenties.

Een welkome plek
Het congres zoomt in op ‘The art of belonging’: **iedereen doet ertoe en voelt zich welkom**. Ieders eigenheid en talent wordt gezien en gewaardeerd, in tegenstelling tot de ongelijkwaardigheid, exclusie en stigma die we wereldwijd waarnemen.

Ondersteuning voor iedereen
We willen doen wat we zeggen! We zetten op ons congres in op toegankelijkheid. Met een **ondersteuningsbalie** (support bar) organiseren we ondersteuning voor iedereen die dit wenst of nodig heeft. We hebben fluistertolken, gebarentolken, schrijftolken, mensen die je de weg wijzen, plekken om tot rust te komen, ... Mensen die geen Engels praten kunnen rekenen op onze vertalers en fluistertolken. We hebben ook workshops in helder taalgebruik, en creatieve workshops die mensen uitnodigen tot anders leren dan in verbale taal.

Congresboek
We creëerden een congresboek met blanco ruimte voor je eigen gedachten, woorden en tekeningen. Tijdens ons congres zijn er workshops die toegankelijk zijn voor een breed publiek, ook voor mensen die geen Engels spreken of begrijpen. Deze workshops duiden we aan met een icoon en met het NL symbool. De meer academische workshops en lezingen zijn niet aangeduid met een icoon of vertaling in het boek.
Als je hulp nodig hebt bij het congresboek, bijvoorbeeld om mee te kijken bij het maken van je keuzes, voel je vrij om ondersteuning te vragen aan onze balie.
Als je een vertaling nodig hebt of andere hulp om te kunnen genieten van de wat meer academische of abstracte workshops, laat het ons weten.

We leren allemaal anders
We zijn verschillend. We communiceren en leren allemaal op een andere manier. Ons congres biedt een bijzonder **kleurrijk palet** aan: lezingen, posterpresentaties theater, muziek, dans, actieve workshops en verdiepende academische uiteenzettingen wisselen elkaar af.
Daarnaast is er een ‘tekenlaboratorium’, stand-up comedy, ruimte voor ‘chillen’ en rust, lekker eten, drinken en kansen tot ontmoeten.
Het **congresboek** bevat zowel beeld als taal om het voor iedereen zo duidelijk mogelijk te maken. We doen hard ons best om dit congres zo toegankelijk mogelijk vorm te geven. Maar wij zullen zeker iets vergeten zijn. Wat voor de ene persoon goed werkt, werkt niet voor de ander.
We zullen elkaar ook hierbij ondersteunen zodat we allemaal kansen krijgen om te leren. Zodat we allemaal inspiratie opdoen en genieten van fijne ontmoetingen en nieuwe ideeën.
Hartelijk dank aan alle auteurs van de abstracts in dit boek, aan alle vrijwilligers, collega’s en ondersteunende partners.

We wensen jullie allen levendige discussies, gedeelde interesses, nieuwe vriendschappen en – heel belangrijk – wij hopen dat jullie je hier thuis mogen voelen!

Namens de congrescommissie,

Alice Schippers,
voorzitter

HOTEL CASA

Space, Room for belonging

Having ‘the right to belong’ is not enough. We need room for belonging, also at our conference. DSiN wants to create a welcoming space within hotel CASA with creative and inspiring workshops, with knowledge through text, images, voice, music, dance, film and meeting. The support bar facilitates support in a way that everyone feels welcome to ask for it. The conference book in two languages gives overview and invites you to write and to draw on your impressions and experience of our conference. Let your own creativity work and feel at home in Amsterdam!

www.hotelcasa.nl

HOTEL CASA

Ruimte, Plek waar je je geborgen mag voelen

Het recht hebben om erbij te horen, dat is niet voldoende. We hebben plekken nodig waar we ons goed en geborgen voelen. We hebben ruimtes nodig waar we kunnen floreren en bijdragen.

Zo’n ruimte willen wij tijdens ons congres creëren. In het hotel CASA hotel vond DSiN een welkome plek.

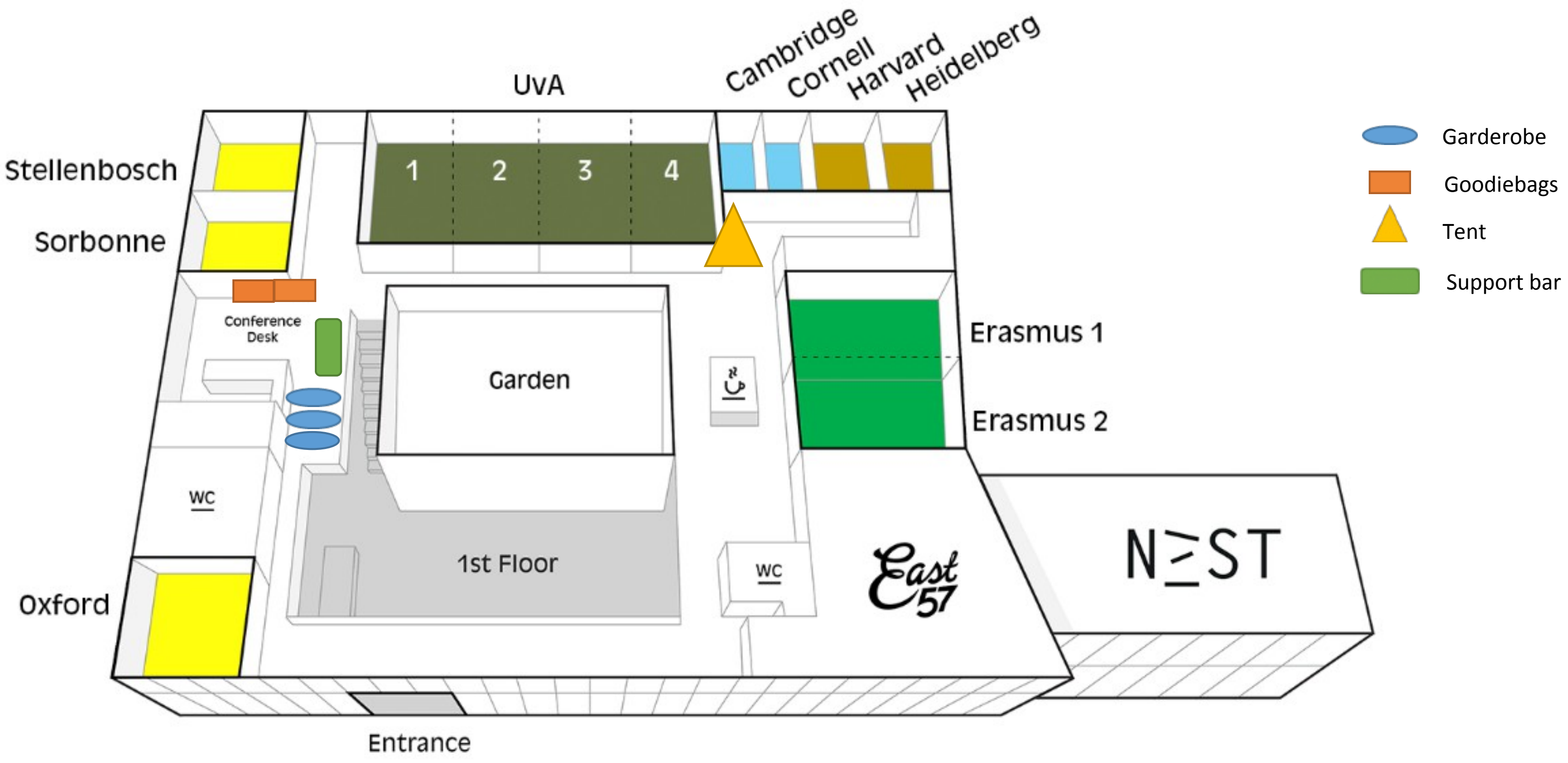
Met creatieve en inspirerende workshops willen we iedereen toegang geven tot kennis via woord, beeld, stem, muziek, dans, film en ontmoeting.

Bij de ondersteuningsbalie kan ieder terecht voor ondersteuning of gewoon voor gezelligheid. Het congresboek – gedeeltelijk in twee talen – geeft overzicht en nodigt uit om je ervaringen, impressies en input tijdens het congres op te tekenen.

Laat je creativiteit werken en voel je welkom hier in Amsterdam!

www.hotelcasa.nl

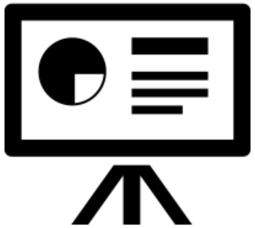
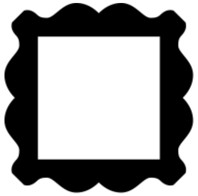
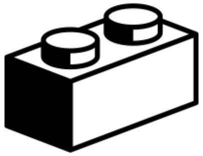
FLOORPLAN


UvA
Cambridge
Cornell
Harvard
Heidelberg
Stellenbosch
Sorbonne
1
2
3
4
Conference Desk
Garden
Erasmus 1
Erasmus 2
WC
1st Floor
WC
East 57
Oxford
NEST
Entrance
Garderobe
Goodiebags
Tent
Support bar

Description of figures/Legenda

Figure/Figuur	English	Nederlands
	Story in the form of online blog	Een verhaal in de vorm van een blog op internet
	Photography	Fotografie
	Dance	Dans
	Discussion or group conversation	Discussie of groepsgesprek

Figure/Figuur	English	Nederlands
	Drawing workshop	Workshop met tekenen
	Use your imagination	Je fantasie gebruiken
	Film or documentary	Film of documentaire
	Storytelling	Verhaaltjes

Figure/Figuur	English	Nederlands
	Picture presentation	Diavoorstelling
	Paintings	Schilderijen
	Presentation	Presentatie
	Different forms of art	Verschillende vormen van kunst
	Mindmapping with use of lego	De gedachten uiteenzetten met behulp van lego

Figure/Figuur	English	Nederlands
	Music	Muziek
	Theatre	Theater
	Dutch	Nederlands

Cultural Programme

United by music, All Star band

Music, Live performance

United by Music will be singing the blues on our conference!! The story is about how blues and gospel music inspired African Americans when they had no rights and no freedom, to transcend their crippling sorrow and pain. United by Music believes in the statement: all people are created equal and as such, should be given equal opportunities. People with intellectual disabilities often do not get those opportunities. It is frustrated to have a dream to perform on stage, only to be told that your disability makes you unacceptable, or unprofessional as a band member. United by Music gives people the chance to prove what they can do as musicians, dancers, performers and singers.

www.unitedbymusic.nl

Cultureel programma

United by music, All Star band

Muziek, Live optredens

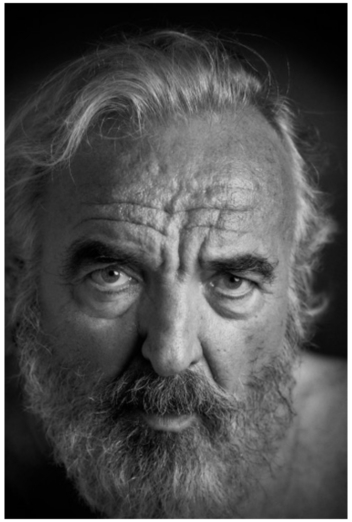
United by Music zingt voor ons de Blues! Tien zeer verschillende persoonlijkheden vormen samen de United by Music All Star Band. Niettemin hebben ze allemaal één ding gemeen: talent. Deze band is actief sinds 2010 en 300 optredens, 10 landen, 8 tours en meer dan 100.000 toeschouwers verder is de band uitgegroeid tot een professionele band die keer op keer een unieke show verzorgt. Het niveau van de artiesten is over de jaren ontzettend gestegen en United by Music wordt dan ook gevraagd voor verschillende grote festivals. Zo stonden de artiesten onder andere op het Hookrock Festival in België, Solund Festival in Denemarken, Morodalfestivalen in Noorwegen, Redwood city Blues Festival in Amerika, Big Rivers in Dordrecht, Roder Markt in Roden en Jazz Festival in Hillegersberg. Hun hoogtepunt beleefde ze in juli 2012 bij het Safeway Waterfront Blues Festival in Portland, het op één na grootste bluesfestival in Amerika. Hier gaven zij een optreden op het hoofdpodium voor meer dan 15.000 mensen.

www.unitedbymusic.nl

Michel

An actor loses words

Film



photographers/fotografen:
Margot Vos / Bas Bijvank

Michel van Dousselaere (Gent, 1948) is an actor. In 2014 they discovered a rare form of progressive aphasia, a brain disorder that affects the speech centre. In the documentary Michel we see how he copes with losing his words and therefor his ability to practice his yearlong profession.

Together with his wife Irma Wijsman he searches for new ways to express himself, to stay on point and to say goodbye in an impressive way to his life as an actor.

His farewell part in the theatre play Borgen; the medical appointments in the Alzheimer centre; boxing to drumming lessons; reactions from friends and colleagues who are trying to imagine how it must be to have words in your head but are unable to let them out.

We see the first years after the diagnoses, and we see how language determines our identity and what it means to redefine and rediscover your own self.

And the film shows two strong people who with much love, and sadness together with humour take back charge of their own life after such a dramatic turn.

Saturday December 2nd a 30 minute preview (English subtitles) will be shown at the 3rd International Disability Studies Conference ‘The Art of Belonging”.

Monday December 11th, the film will premiere nationwide.

A film by Irma Wijsman and Patrick Minks
With Michel van Dousselaere
An idea of Irma Wijsman

Michel

Acteur verliest de woorden

Film

Michel van Dousselaere (Gent, 1948) is acteur. In 2014 is bij hem een zeldzame vorm van progressieve afasie ontdekt, een hersenaandoening die het spraakcentrum aantast.

In de documentaire Michel is te zien hoe hij omgaat met het verlies van zijn woorden en daarmee van het vak dat hij al zo lang uitoefent.

Samen met zijn vrouw Irma Wijsman zoekt hij naar nieuwe manieren om zich uit te drukken, om scherp te blijven en om op indrukwekkende wijze afscheid te nemen van zijn leven als acteur. Van zijn afscheidsrol in de voorstelling Borgen tot de medische consulten bij het Alzheimercentrum; van de boks- en drumlessen tot de reacties van vrienden en collega’s die zich proberen te verplaatsen in een situatie waarin de woorden nog wel in je hoofd zitten terwijl je ze niet meer kunt uitspreken.

Door mee te kijken naar de gebeurtenissen in de eerste jaren na de diagnose wordt zichtbaar hoe taal onze identiteit bepaalt en wat het betekent om jezelf te moeten hervinden. Tegelijkertijd laat de film twee krachtige mensen zien die met liefde, verdriet en humor de regie nemen over een dramatische wending in hun leven.

Op zaterdag 2 december wordt een preview van 30 minuten (engels ondertiteld) vertoond op het congres The Art of Belonging.

Maandag 11 december is de landelijke premiere.

Een film van Irma Wijsman en Patrick Minks
met Michel van Dousselaere
naar een idee van Irma Wijsman

Robin Hood, Brother Tuck, back to the woods?

Jan Troost & Jeroen Zwart, 2017

Theatre, Live performance

Jan Troost, Dutch activist, believes in the power of creativity and humour in the fight against ableism and discriminiation of people with disabilities.
With his movement ‘Back to the woods’ Troost shows his critical vision on how society excludes people and creates non-inclusive non-interesting places for people with disabilities.
On our conference we create a small forest in which Jan Troost will play hide and seek with the audience, raising the question: “Where do you belong?”.

www.terugnaardebossen.nl

Robin Hood, Broeder Tuck, terug naar de bossen?

Jan Troost & Jeroen Zwart, 2017

Theater, Live voorstelling

Wij – personen met een beperking – horen niet thuis in een internaat, verscholen in de bossen. Maar midden in de samenleving. En we hebben – in die samenleving – recht op goed onderwijs, een goede woning, werk, gezondheidszorg, privacy,…
Goede ondersteuning, dat wil DSiN ook bieden op dit congres, voor iedereen.

Robin Hood en Broeder Tuck heten jullie welkom en wijzen de weg naar de Support Bar: de bar waar iedereen kan gaan hangen, een praatje maken, of vragen om hulp.
Robin Hood en Broeder Tuck bieden jullie ook een plek aan waar je kan tekenen over wat maakt dat je je hier of ergens anders thuis voelt? Wat is ‘belonging’ voor jou? Zeg het ons met een tekening!

www.terugnaardebossen.nl

I am, so I belong

Storytelling about arts of belonging by people who dare to be themselves!

Margriet van Kampenhout, 2017

Theatre, Life performance

There is a lot to study about the Art of Belonging. And also much to tell, as Margriet van Kampenhout is going to do. In her 20 minutes' presentation, she will highlight some memorable initiatives people take to make themselves and others feel and be respected members of their community. To achieve that, all they do is dare to be and to express their true selves. Margriet feels honoured to pass these creative and caring examples on to you today. Besides speaking about those, she will also go into some recognizingly painful situations in which the right intentions appear to generate the opposite outcomes than building the bridge.
In those cases, people get the feeling that they themselves or others don't or should not belong.

Margriet will always link these mismatches between intentions and effects to her message that, however unfortunate an action may turn out, it should never be able to **exclude** the person from the community that is the most essential of all: 'human mankind'. "Because in an **inclusive** society belonging is, and should be looked upon as, an unconditional and integral part of being present."
Without ridiculing, Margriet will do anything (out-of-the-box or even slightly over the edge) to underpin her conviction that the pure fact of existing makes people belong. She sincerely hopes that her stories of all these beautiful Arts of Belonging, by all these 'ordinary people', will invite you to keep on looking for them in your own community as well. "Because wouldn't it be promising that we can enhance to**gether**ness by **gathering** narratives about all the different Arts of Belonging?"

www.argentaconsult.nl

Ik ben, dus ik hoor erbij

Verhalen over de kunst van het 'erbij horen' door mensen die zichzelf durven zijn!

Margriet van Kampenhout, 2017

Theater, Live voorstelling

Er valt veel te bestuderen over de kunst van het 'erbij horen', van je thuis voelen waar en bij wie je bent. Dat er ook veel over te vertellen valt, zal Margriet van Kampenhout ons bewijzen.

Ze vertelt enkele anekdotes over bijzondere manieren waarop mensen zichzelf en anderen laten voelen en ervaren dat ze een wezenlijk deel uitmaken van de groep. Margriet voelt zich vereerd dat ze deze creatieve en zorgzame voorbeelden aan haar toehoorders mag doorgeven. Naast deze voorbeelden waar het allemaal goed afloopt, zal ze ook een paar herkenbaar pijnlijke situaties beschrijven. Daarin blijken de ongetwijfeld goede bedoelingen het tegenovergestelde te veroorzaken, waardoor mensen zich, nog meer dan eerst, afgewezen voelen.

Margriet zal deze mismatch tussen bedoeling en effect altijd koppelen aan haar boodschap dat, hoe onfortuinlijk een initiatief ook kan uitpakken, het nooit tot gevolg zou mogen hebben dat een persoon wordt buitengesloten van de meest basale gemeenschap die er bestaat: de mensheid. Zij is overtuigd dat het pure feit van bestaan ieder mens een eigen, onvoorwaardelijke, plek bezorgt in de inclusieve samenleving,

Altijd respectvol en soms onverwacht, zal Margriet alles uit de kast halen om die overtuiging kracht bij te zetten. Ze hoopt oprecht dat haar voorbeelden u zullen uitnodigen om ook in uw eigen omgeving op zoek te gaan naar markante verhalen over al die mensen die 'The Art of Belonging' koesteren en vertalen naar acties die dat waarmaken.

www.argentaconsult.nl

Drawing Lab

Sofie Sergeant, 2017

Workshop

The drawing lab is a research method by Sofie Sergeant and was described in the book 'Disability Studies in de Lage Landen', available on this conference.

At the conference, we have created a drawing lab, in which we invite people to draw.

The drawing lab assistants can be recognized by their lab-apron. The lab guests will be guided through stage 1 through 6 in a prior determined pattern.

But that is all the information we will give away for now…

Artist Saar De Buysere will be present on Friday and available to assist lab guests to bring their ideas to life.

Tekenlab

Sofie Sergeant, 2017

Workshop

Het tekenlabo is een onderzoeksmethode, bedacht door Sofie Sergeant en beschreven in 'Disability Studies in de Lage Landen', op dit congres ook te koop aangeboden.

Bij een tekenlabo nodig je mensen uit om te tekenen.
De labo-medewerkers zijn herkenbaar aan hun laboschort.
De labogasten worden geleid van fase 1 tot 6 volgens een vastgelegd patroon.

Meer kunnen we hier niet verklappen…

Kunstenaar Saar De Buysere is op vrijdag aanwezig om labogasten te helpen bij het vorm geven aan hun ideeën.

The traveler and the reproduction

Saar De Buysere, 2017

Oil on canvas

Saar De Buysere, Belgian artist, integrates everyday objects like sand, flowers, newspapers, coffee or salt into her sculptures and drawings. Dreamy and nature-inspired mountain views and landscapes, can be examined as social, economic, touristic and geological phenomenon’s. Like an architect she unites different elements. The bricolage expresses a relaxing and ideal environment, a place for belonging.

De Buysere created ‘a mixed forest’ for DSiN on which the Dutch cartoonist René Krewinkel (www.krewinkelrijst.nl) drew his cartoons. The trees and the cartoons can be seen on the DSiN website and will be part of the exhibition in CASA hotel during and after the conference.

www.saardebuysere.blogspot.com

De reiziger en de reproductie

Saar De Buysere, 2017

Textiel op doek

Belgisch kunstenaar Saar De Buysere onderzoekt nieuwe technieken en werkt met niet-evidente materialen. Ze recupereert en herwerkt vorige kunstwerken. Toch gaat ze van klassieke elementen: een bloemstuk, een portret, een berg. Deze beelden vindt Saar De Buysere in oude tijdschriften, schilderijen en postkaarten. Als een stadsplanner of architect brengt ze verschillende elementen samen. Zo ontstaat er iets van een ideale omgeving, een plek waar je je thuis zou kunnen voelen, die ontspanning uitstraalt.

Voor DSiN ontwierp De Buysere de bomen, die structuur en beeld geven aan de studie- en lesmaterialen op de website van DSiN.

Op basis van deze bomen maakte René Krewinkel (www.krewinkelrijst.nl) cartoons.

De bomen en de cartoons worden tentoongesteld tijdens het congres.

www.saardebuysere.blogspot.com

Cartoon ‘Arts-based research’ by Saar De Buysere & René Krewinkel. Developed for DSiN.

General information

Contact details VUmc Academy conference organisation
Telephone: +31 (0)20-4448444
Email: events@vumc.nl

Opening hours registration desk
Venue: Hotel Casa

– Thursday, November 30th	11.00-19.00 hours
– Friday, December 1st	08:30-17:30 hours
– Saturday, December 2nd	08.30-14.00 hours

Registration fees
The conference fee includes:

- welcome reception on Thursday, October 31st
- 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
On the last day of the conference you will receive a digital evaluation form. You are kindly requested to complete this form.

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 registration desk/support bar.

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 Hotel Casa for the locations of the accessible toilets. Hotel Casa 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/support bar.

Language
The languages at this international conference are spoken English, some talks are in Dutch and we have the use of International Sign language. For interpreters please contact the support bar.

First aid
If any participant requires first aid, please contact the main registration desk/support bar.

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

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 3rd Disability Studies International Conference 2017, please contact the VUmc Academy organization, email: events@vumc.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 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 Hotel Casa 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 hotel Casa in Amsterdam is close to Schiphol International Airport and the city center. There are excellent rail, tram and bus connections between Hotel Casa and the airport. Information on wheelchair accessibility of the Amsterdam public transport and accommodation you can also find at the website www.toegankelijkamsterdam.nl.

Programme

Thursday, November 30

Chair: W. De Gooyer, A. Schippers

11.00 – 19.00 hrs **Registration**

12.30 – 16.30 hrs **Pre-Conference Workshops IASSIDD Academy**

- Workshop 1: *Inclusive research: practices and beyond*
  Moderator: A. Schippers
  T. Büchner, E. García Iriarte, M.L. Yap, M. Turley, F. Angus
  Sorbonne
- Workshop 2: *Living with Autism*
  Moderator: M. Waltz
  M. Waltz, D. Milton
  Stellenbosch

16.30 – 18.00 hrs **Reception**
Erasmus foyer

18.00 – 18.30 hrs **Opening Conference**
United by Music, All Star Band
Main Lecture Room

18.30 – 19.30 hrs **Keynote Lecture I**
Navigating the art of belonging, my convoluted journey
Charlotte V. Mcclain-Nhlapo, co-speaker Johan Wesemann

Friday, December 1

Chair: Tineke Abma

08.30 – 17.30 hrs **Registration**

09.15 – 10.15 hrs **Keynote lecture II**
Chronicles of belonging: multi-media stories of 'autism' and 'inclusion'
Katherine Runswick-Cole, co-speakers Ans van Berkum, Alex Naber
Main Lecture Room

10.15 – 10.45 hrs **Coffee & tea break**
Foyer Erasmus

10.45 – 12.00 hrs **Parallel Sessions**

- **Stream Representation & Stigma**
  Moderator: T. Abma
  W. van Brakel *Introduction stream/mini keynote*
  1. L. Hinderks, C. Tijsseling & J. Thijs *Do Deaf and hard-of-hearing people belong to each other? Issues of identity and in-group discrimination* (O-01)
  2. G. Rabbers *Combatting Sigma on mental illnesses: what works?* (O-02)
  3. W. van Brakel, R. Peters, Dadun, M. Lusli, M. Zweekhorst, J. Bunders, Irwanto *The Sari Project: a randomised controlled trial of interventions to reduce stigma in Cirebon, Indonesia* (O-03)

  Foyer Erasmus UvA1

- **Stream Belonging & Context**
  Moderator: G. Sterk
  P. Devlieger *Introduction stream/mini keynote*
  1. A. Niemeijer, I. Blockmans *Do I belong to a collective experience? A duo-ethnographic enquiry into patient experience and representation* (O-18)
  2. L.Y. Bulk, M. Smith *Being blind in a sighted world: Exploring experiences, challenging perceptions* (O-19)
  3. P. Devlieger *Belonging in the diaspora via affinities for people with disabilities back home: The case of the Congolese diaspora in Belgium* (O-20)

  Oxford

- **Stream Disability History & Rights**
  Moderator: P. van Trigt
  P. Verstraete *Introduction stream/mini keynote*
  1. M. De Picker, P. Verstraete *An eye-opening close-up of the work life of physically disabled labourers in Belgium* (O-36)
  2. D. Blackie *Disability and Masculinity in Victorian Britain* (O-37)

3. A. van Ertvelde *Writing to belong.Disability memoirs from across the Iron Curtain* (O-38)

Main Lecture Room

- **Stream Inclusive & Creative Methods**
  Moderator: J. Kool
  E. García Iriarte *Introduction stream/mini keynote*
  1. T. Frankema *Reflection of a 3-year collaboration between researchers with and without intellectual disabilities* (O-49)
  2. A.R. Correia *Inclusive research: How do we start?* (O-50)
  3. E. van Zadelhoff *Working together with people who are communication vulnerable in research* (O-51)

  Erasmus 1

- **Stream Inclusive Education & Work**
  Moderator: R. Maier
  T. Büchner *Introduction stream/mini keynote*
  1. A. van Westen *Educating Ronald* (O-68)

  Sorbonne

- **Stream (Family) Quality of Life**
  Moderator: A. Schippers
  A. Schippers *Introduction stream/mini keynote*
  1. A. Hiddinga *The art of signing: generational differences in Deaf people's signing practices* (O-82)
  2. B. Tefera Nidaw *The Grace of Motherhood* (O-83)
  3. G. van Hove *Experiences of fathers of children with disabilities: a forgotten chapter in family research?* (O-84)

  Stellenbosch

12.00 – 13.00 hrs Postersession & Lunch

Posters:

1. Hanneke van der Meide, Pascal Collard , Truus Teunissen:
   "The experience of body awareness in people with Multiple Sclerosis and people with a chronic lung disease" (P-1)

2. So Young Kim, Jong-Hyock Park: "The Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities: Necessity and Implication beyond Disability Discrimination Act" (P-2)

3. Jong Hyock: "Health policy suggestions from disability to possibility in medical education" (P-3)

4. Ariel Tenenbaum, Shirli Werner, Liron Benisti: "Inclusion and reverse inclusion in preschool programm -"Shalva" organization" (P-4)

5. Shade A. Osifuye: "Sustainability, Access, and Retention for Students with Disabilities in Kenya" (P-5)

6. Wil IJzereef: "Friends! Social participation for all students at The Hague University" (P-6)

7. Janice Sandjojo: "Preliminary evaluation of a self-management training for people with intellectual disabilities" (P-7)

8. Janice Sandjojo: "Promoting independence in people with intellectual disabilities: Results from a focus group study" (P-8)

9. Marjon Verboom, Wim Smeets, Michel Wensing: "The Grief-Cube © : a tool to support people with ID in their grief" (P-9)

10. Femke Bannink: "Recognition and the role of family in belonging, being and becoming in Uganda" (P-10)

11. E.F. Taminiau: "Inclusive Research" (P-11)

13.00 – 14.00 hrs Parallel Sessions

- **Stream Representation & Stigma**
  Moderator: P. Bijl
  1. M. Parry *Disability on Display: New Approaches in European Medical Museums* (O-04)
  2. N. Van Vuuren *To see or not to see: exhibition experience from the perspective of wheelchair users* (O-05)

3. D.A.J. Korving, E. Hiddinga *Diversifying the Collections: The Intersection of Race and Disability in Museum of the Mind Het Dolhuys* (O-06)

UvA 1

- **Stream Belonging & Context**

  Moderator: G. Sterk
  1. T. Bos *Festival Vrolijk (The Happy Festival), a creative cultural celebration in a co-production by people 'with' and 'without' intellectual disabilities for the city of Gouda (*O-21)
  2. M. Benoist *Where are you from? Feeling at home in a nursing home* (O-22)

  Oxford

- **Stream Disability Historie & Rights**

  Moderator: M. Waltz
  1. D.C. Jackson-Perry *'I'll Tick Heterosexual and Leave It at That': Autism, Sexuality, and the Mythical Norm* (O-39)
  2. J. Bahner *Cripping sex education: lessons to be learned from a programme aimed at young people* (O-40)
  3. A. ter Haar, J. Barendrecht *Powerfull connections with impact by diversity and mass* (O-41)

  Main Lecture Room

- **Stream Inclusive & Creative Methods**

  Moderator: M. Bakker
  1. J. Oonk, S. Lamers, E. Straver *Flirt Fantasies - What do you think when you look at me? Choreographing, performing, and appreciating inclusive arts as a 'practice of knowing'* (O-52)
  2. M. Karasaki, J. Oonk *Making a more inclusive art world: belonging, relating and creating* (O-53)

  Erasmus 1

- **Stream Inclusive Education & Work**

  Moderator: L. Peters-Greijn
  1. S. Werner, L. Benisti, A. Tenenbaum *Impact of participation in academic friending courses on individuals with disabilities* (O-69)
  2. M. Gerritsen-Ververs, L. van Hal, L. Verharen, J. Meesters *Adequate education and adequate occupation. What is adequate in the social environment of youth with a disability?* (O-70)
  3. E. García Iriarte, A. Swift, R. McConkey, R. H. Gillligan, P. Curry *School and social participation for children with disabilities: What happens when ethnicity and migration also come into play?* (O-71)

  Sorbonne

- **Stream (Family) Quality of Life**

  Moderator: K. Runswick-Cole
  1. A. Eichengreen, A. Zaidman-Zait *Growing up with a sibling who is deaf/hard-of- hearing like myself: Retrospective accounts* (O-85)
  2. M. Vandecasteele *RE-TOUCH Narratives of siblings* (O-86)

  Stellenbosch

14.00 – 14.15 hrs **Session switch**

14.15 – 15.15 hrs **Keynote lecture III**
Suppose it will be normal to be different
Trudy Dehue
Main Lecture Room

15.15 – 15.30 hrs **Coffee & tea break**
Foyer Erasmus

15.30 – 16.30 hrs **Parallel Sessions**

- **Stream Representation & Stigma**

  Moderator: W. van Brakel
  1. M. Baadenhuijsen *Experience All Inclusive, how simulations have a positive effect on stigma* (O-07)
  2. M. van der Werf, G. Gortworst *Card Game 'Screw loose?' Let's talk about mental health and quality of life!* (O-08)

  UvA 1

- **Stream Belonging & Context**

  Moderator: G. Van Hove
  1. V. van Druten, M. Visse, N. Smulders *A voice to belong:*

how people with intellectual disabilities experience participation in their neighborhood (O-23)
2. S. Hilberink, M. Klem, J. de Lange, M. Cardol *Disability Management as effort to shape citizenship* (O-24)
3. J.P. Wilken, J. Knevel *Social Inclusion: working on belonging* (O-25)

Oxford

- **Stream Disability Historie & Rights**
  Moderator: D. Blackie
  1. S. De Schutter *Of History and Membership: Tanzanian Disability Activists, Global Citizenship and History* (O-42)
  2. P. Verstraete *Listening to emancipation: Sound and the liberation of people with a visual disability in Belgium, 1900-1940* (O-43)
  3. J. Wesemann *The Art of Belonging: A Personal History of the Disability Movement at the European level* (O-44)

  Main Lecture Room

- **Stream Inclusive & Creative Methods**
  Moderator: J. Kool
  1. D. Kal, G. Bos, artists of studio "bij Johannes" *In praise of visibility: how art can change our perspectives on disability* (O-54)
  2. K. Tamminga, H.Blom-Yoo *Inclusion and Churches: an Ecclesiological Contribution* (O-55)
  3. J. Blume, N. Vanuccini *RAMP: How a struggle over access inspired a beer* (O-56)

  Erasmus 1

- **Stream Inclusive Education & Work**
  Moderator: H. Meininger
  1. J. Jansen, N.R. Vonk *Transforming vision into useful policy for all students in higher education* (O-72)
  2. N. Tal-Alon, O. Shapira-Lishchinsky *Ethical Dilemmas of Teachers with Physical Disabilities for Integration into Schools* (O-73)
  3. H. Vandenbussche, E. de Schauwer *The pursuit of belonging: insider perspectives on the meshwork of participation in education* (O-74)

  Sorbonne

- **Stream (Family) Quality of Life**
  Moderator: T. Büchner
  1. J. Beernink, M. Nijland *Flourishing: Training program for professionals and parents of people with severe disabilities* (O-87)
  2. J. Sandjojo, A. Zedlitz, W. Gebhardt, J. Hoekman, E. Dusseldorp, J. den Haan, A. Evers *Training support staff to promote self-management in people with intellectual disabilities* (O-88)
  3. R. Kwekkeboom *Those who care, need to belong as well - young carers* (O-89)

  Stellenbosch

16.30 – 16.45 hrs Session switch

16.45 – 17.45 hrs Parallel Sessions

- **Stream Representation & Stigma**
  Moderator: K. Runswick-Cole
  1. G. Rebergen *Digging tunnels with songs of experiences of the (dis)abled* (O-09)
  2. N. Pérez Liebergesell, P.W. Vermeersch, A. Heylighen *Disability experience through the body of a designer: the case of architect Marta Bordas Eddy* (O-10)
  3. S. Vertoont *Disabled images: a quantitative content analysis on disability television representations in Flanders* (O-11)

  UvA 1

- **Stream Belonging & Context**
  Moderator: A.Schippers
  1. E. García Iriarte, K. Stober, R. Kidd, R. McConkey *Achieving social inclusion through personalised living and support* (O-26)
  2. B. Prins *The art of belonging, how do you know if you take part in society as a full member of society?* (O-27)
  3. A. Brummel *Level of social connectedness in neighborhoods as opportunities for social inclusion* (O-28)

  Oxford

- **Stream Disability Historie & Rights**
  Moderator: M. Stein
  1. R. Smárason, G. Björnsson, K. Björnsdóttir *Equality for all* (O-45)
  2. T. Mol, M. Waltz, E. Gittins *The UN CRPD ratified; the first step to a barrier-free society?* (O-46)
  3. M.M. Waltz, E. Gittins, T. Mol *Disability, access to food and the UN CRPD: Navigating a rights-based equality discourse in the Netherlands* (O-47)

  Main Lecture Room

- **Stream Inclusive & Creative Methods**
  Moderator: H. Meininger
  1. S. Woelders-Peters, A. Hendrikx, S. Metselaar, K. Schipper, T. Abma, B. Molewijk, *Caring relationships around acquired brain injury (ABI): mapping moral complexities* (O-57)
  2. I. van de Putte, E. De Schauwer *Glimpses of the life of Anna – working with autO-etnography as a support worker* (O-58)
  3. H. Peels, Britt (Beau) *Collaborative Research: Power and Possibilities* (O-59)

  Erasmus 1

- **Stream Inclusive Education & Work**
  Moderator: M. Cardol
  1. M. Cardol *Roundtable Higher Education & Disabiilty Studies* (O-75)

  Sorbonne

- **Stream (Family) Quality of Life**
  Moderator: B. Tefera Nidaw
  1. D. Stienstra *Abrupt inclusion: People with disabilities in transitions, crises and change* (O-90)
  2. D. Kidd *Belonging, Meaning, and Identity: Living with Severe Traumatic Brain Injury* (O-91)
  3. A. Nieuwenhuijse, D. Willems, J. van Goudoever *Belonging as an important element of QoL in persons with PIMD: A qualitative study on physicians' perceptions* (O-92)

  Stellenbosch

18.30 – 21.30 hrs **Conference dinner**
Stand-Up Comedy Margriet van Kampenhout
Restaurant

Saturday, December 2
Chair: J. Goldschmidt

08.30 – 10.00 hrs **Registration**

09.00 – 10.00 hrs **Keynote lecture IV**
The first and second decades of the CRPD
Michael Stein, co-speaker Dick Houtzager
Main Lecture Room

10.00 – 11.00 hrs **Parallel Sessions**

- **Stream Representation & Stigma**
  Moderator: P. van Trigt
  1. E. Lüthi *The Psychiatric Archipelago: Towards an Intersectional Understanding of Psychiatry* (O-12)
  2. C. Platenkamp *A Dutch way: building bridges between practice and science with stories on* www.patientervaringsverhalen.nl (O-13)
  3. L. Van Goidsenhoven, E. De Schouwer *Autism Matters, Doesn't it? Analyzing the emergent subjectivities in Tistje – an experience blog on autism* (O-14)

  UvA 1

- **Stream Belonging & Context**
  Moderator: J. Goldschmidt
  1. E. Heppe, S. Kef, C. Schuengel *Improving social participation of adolescents with visual impairments: a mentoring intervention* (O-29)
  2. C. Tijsseling *The role of belonging in quality of life of deaf adults in a home counseling program* (O-30)
  3. M. Nooren, I. Loe *Belang van methodiek 'in dialoog gaan' als bijdrage aan inclusiviteit, participatie en positief zelfbeeld van mensen met een verstandelijke beperking* (O-31)

  UvA 2

- **Stream Belonging & Context**
  Moderator: G. Sterk
  1. K. Kim, E. Woo Joo *Why are middle-aged people with intellectual disabilities still lonely in their communities in Korea?* (O-32)
  2. G. Bos, R. van den Bosch, M. Heinze *Participatory and responsive research into a 'Curriculum Experential Expertise' for people with an intellectual disability* (O-33)
  3. G. Nass, H. Van Dijk, R. Oomen *Empowerment through personal development and cooperation* (O-34)

  Oxford

- **Stream History & Rights**
  Moderator: L. Peters-Greijn
  1. J. Holla, E. Jongerius, J. Smits *Life After Violence, how women with intellectual disabilities cope with institutionalised violence* (O-48)

  Main Lecture Room

- **Stream Inclusive & Creative Methods**
  Moderator: A. Schippers
  1. H. Sandvoort, S. Sergeant, K. van den Boogaard, E. Taminiau *'Collaboration in research'* (O-61)

  Erasmus 1

- **Stream Inclusive & Creative Methods**
  Moderator: M. Bakker
  1. A. Hiskes *All the limbs we cannot see: a comparative reading of Michelangelo's David and Berlinde de Bruyckere's Into One-another III, to P.P.P.* (O-62)
  2. Ymke Kelders. *Rolling Moms*

  Erasmus 2

- **Stream Inclusive Education & Work**
  Moderator: H.Peels
  1. H. Ebben *Studying English and Dutch personal accounts from a Critical Autism Studies perspective* (O-76)
  2. H. N'kakudulu *Experience of the KIKESA Center in the field of rehabilitation: assessment of 50 years* (O-77)
  3. L. Blankenstein *Autism Ambassador: Impact on workplace by contributing to inclusiveness and diversity* (O-78)

  Sorbonne

- **Stream (Family) Quality of Life**
  Moderator: M. Waltz
  1. D. Milton *How are notions of wellbeing and belonging constructed in the accounts of autistic adults?* (O-93)
  2. E. Olsman, A. Nieuwenhuijse, D. Willems *'Belonging' as starting point to understand QoL of persons with PIMD.A narrative identity approach* (O-94)
  3. K. Klaver, V.Olivier-Pijpers *The art of living and belonging in severely complicated situations.Toward an understanding of the experiences of "challenging behaviour" in long-term care* (O-95)

  Stellenbosch

11.00 – 11.30 hrs **Coffee & tea break**
Foyer Erasmus

11.30 – 12.30 hrs **Parallel Sessions**

- **Stream Representation & Stigma**
  Moderator: W. van Brakel
  1. D. Roth *How Stigma affects us: the voice of self-advocates with intellectual disability* (O-15)
  2. G. Dingler *NSGK Jongerencoach supports youngsters to attain personal goals and increase self determination* (O-16)
  3. F. Bannink *'I want to go outside at playtime', children's perspectives on inclusion in Uganda* (O-17)

  UvA 1

- **Stream Belonging & Context**
  Moderator: R. Maier
  1. R. Maier, F. Nijboer *"New technologies and belonging: enhancement and dilemmas"* (O-35)

  UvA 2

- **Stream Inclusive & Creative Methods**
  Moderator: G. Van Hove
  1. M. Zaagsma, A. Schippers, K. Volkers, G. van Hove *Exploring 24/7 online support through inclusive research*

(O-64)
2. M. Bakker, L. Van de Merbel *Mind mapping in reciprocal participatory research* (O-65)
3. M. Wouda, H. Sandvoort, S. Sergeant, S. van Wijngaarden, P. Sterkenburg *A joint venture: persons with a disability, their representatives and researchers working side- by-side in scientific research projects* (O-66)

Main Lecture Room

- **Stream Inclusive & Creative Methods**
  Moderator: T.L. Cone
  1. T. Cone *Moving Thought: currents in the hidden choreography in our lives* (O-67)

  Erasmus 1

- **Stream Inclusive & Creative Methods**
  Moderator: A. Schippers
  1. M. Visse, A. Niemeijer, A. Schippers, J.Kool, T. Teunissen, S. Rodenburg *Longing to belong: Proposal of the ‘Art & Care Group’ (Kunst & Zorg)* (O-60)

  Oxford

- **Stream Inclusive Education & Work**
  Moderator: P. van Trigt
  1. E.L. de Vos, R. Prins, T. Carstensen, S. Hultqvist, M. Fuchs, S. Woodin *Young persons with health conditions: measures on prevention of disability benefit and activation* (O-79)
  2. K. Brongers, B. Cornelius, Je. Ham, S. Brouwer *Associations between multiple problems, work status and perceived health among disability beneficiaries* (O-80)
  3. D. Weve *The autism embassy: the autistic colleague acting as a change agent at work* (O-81)

  Sorbonne

- **Stream (Family) Quality of Life**
  Moderator: T. Büchner
  1. N. Grove, S. Piekstra–Zijlstra, A. Piekstra, S. Anisuzzaman–van Hasselt, A. Pilon, S. van Weering-Scholten, A. Linker-van der Wier, A. Garmann, S. Posthumus, S. Piekstra *The art of conversation: finding new ways to talk with Siska.* (O-96)

  Stellenbosch

- **Stream (Family) Quality of Life**
  Moderator: H.Peels
  1. E. Meys, B. Maes, K. Hermans, D. Nijs *Mechanisms and influencing factors in strengthening social networks of persons with disabilities* (O-97)
  2. M. Verdonschot *Arts Therapies in community based treatment teams for people with mild intellectual disabilities* (O-98)
  3. M. Heerings, H. van de Bovenkamp, M. Cardol, R. Bal *Participatory quality improvement of complex relationships in care for people with learning disabilities* (O-99)

  Erasmus 2

12.30 – 13.30 hrs **Closing Ceremony**
Closing: Geert Van Hove
Performance United By Music All Star Band
Main Lecture Room

13.30 – 14.15 hrs **Lunch & Farewell**
Foyer Erasmus

14.00 - 14.30 hrs **Preview: Michel, An Actor loses words.**
A documentary by I.Wijsman and P. Minks
Erasmus 1

Pre-Conference Workshops

IASSIDD Academy

Thursday November 30th, 2017
12:30-16:30 h.

Workshop 1

Inclusive research: practices and beyond

IASSIDD presenters: Tobias Büchner, Edurne Garcia Iriarte,
Mei-Lin Yap, Margaret Turley, Fionn Angus
Moderator: Alice Schippers

Inclusive research can be characterized as democratization of research processes and as such an act of social justice as well. Inclusive research represents people outside the academia as producers of knowledge.
As such, it provides a backbone for conducting research in the field of disability studies, that puts people with disabilities and their allies in an active research role. In this workshop we will engage participants in this ongoing way of opening up valuable knowledge.

The workshop will be facilitated by a group of researchers actively engaged in inclusive research from various European countries.

At the workshop, participants will review current debates on inclusive resarch (e.g., training, dissemination of research). Workshop participants will work on real examples to discuss various methodological approaches to inclusive research.

Workshop 2

Living with autism

IASSIDD presenter: Mitzi Waltz
co presenter: Damian Milton
Moderator: Mitzi Waltz

Autistic people experience barriers to inclusion, participation and belonging in all sectors of life, including education, work, housing, and community life. Sometimes these barriers are physical, such as flickering Web interfaces and fluorescent lights that can prevent use of services or spaces, or trigger seizures. Sometimes they are procedural, for example the use of confusing multi-part instructions, or expectations that everyone can perform social interaction in the same way. Often they are social, with normative beliefs and behaviors placing obstacles in the way of understanding and belonging. Most work in the field of autism has focused on changing autistic people rather than dismantling these barriers.

In our workshop, we will address how the focus can be shifted. We will also discuss practical ways to make places, services and communication more accessible for autistic people, and what policymakers can do to ensure inclusion.

Keynote speakers

Charlotte V. McClain-Nhlapo

Navigating the art of belonging, my convoluted journey

Given our multiple identities and the various communities we belong to -the art of belonging can be messy and complex. The perennial question ‘Who am I?’ Needs to be asked and I will weigh my response to it with an even deeper question: ‘Who are we?’

And how do we interact to write a shared narrative that is informed by our own individual stories. I will explore how different struggles for social justice are premised on universal principles that have guided my work on disability inclusive development and our work as a group more broadly. I will argue that a common narrative underpinned by respect, non-discrimination, solidarity, participation and voice are the hallmarks of belonging. I will talk about how strong communities develop our moral fortitude, build our emotional security and enable us to flourish.

Charlotte V. McClain-Nhlapo is Global Disability Advisor for the World Bank Group and a global thought leader on disability rights and inclusion. She served as USAID’s coordinator for disability and inclusive development, appointed by U.S. President Barak Obama in 2011 to lead the government’s efforts in disability inclusive development, from developing policies and country strategies to technical assistance for program implementation. Prior to this, she worked as a senior operations officer at the Bank to integrate disability inclusive development into operations in the East Asia Pacific and Africa regions and was appointed by President Nelson Mandela to the South African Human Rights Commission focusing on social and economic rights, disability rights and child rights.

Sprekers voor de grote groep

Charlotte McClain-Nhlapo

We zijn allemaal verschillend. En elk van ons is ook anders in andere situaties. We zijn thuis in verschillende plekken en we komen thuis bij verschillende mensen. ‘The art of belonging’ is dus een ingewikkelde zaak en altijd rommelig. De eeuwige vraag ‘Wie ben ik?’ moet gesteld worden en Charlotte Vuyiswa McClain-Nhlapo zal voorzichtig antwoorden met een nog diepere vraag: ‘Wie zijn wij?’. Hoe beïnvloeden wij elkaar en schrijven wij samen een verhaal dat gebaseerd is op onze persoonlijke geschiedenis? Charlotte legt uit hoe wereldwijd ijveren en vechten voor sociale gerechtigheid gestoeld is op principes uit het gevecht voor inclusie van mensen met een beperking. Een verhaal van ‘samen’ is gebouwd op respect, non-discriminatie, solidariteit en participatie en dit leidt naar ‘belonging’. Dit leidt naar ‹erbij horen, je geborgen voelen, een gewaardeerde bijdrage leveren in de samenleving’. Charlotte zal ons toelichten hoe sterke gemeenschappen onze morele kracht en onze emotionele veiligheid waarborgen en het mogelijk maken om te floreren.

Katherine Runswick-Cole

Chronicles of belonging: multi-media stories of ‘autism’ and ‘inclusion’

Shared in this presentation: some stories collected as part of a digital storytelling research project Enacting Critical Disability Communities in Education. This is a two-year international Social Sciences and Humanities Research Council-funded multimedia storytelling project, located in Toronto, Canada, focused on autism and inclusion in schools. The project is led by Patty Douglas, Brandon University, Canada.
The project explores how multimedia storytelling might enhance inclusion by making spaces for a proliferation of representations of autism – beyond the dominant biomedical model of autism as a deficit in need of remedy. The films and storytelling workshops open new meanings around ‘autism’ and ‘inclusion’ and create spaces to think about belonging. In this way, the project aims to make spaces for stories of difference that open-up ways of enacting inclusion differently.
Multi-media stories created through the project’s workshops are short, often first-person films that pair still images, video clips, ambient sound, visual art, voice, music, movement and more to represent the complex experiences that often elude written language or linear narrative structure (Rice et al., 2015). Here, through multi-media storytelling, we follow a tradition of educators how have sought to disclose “the multiple forms of public silencing” (Weis & Fine, 1993 cited in Li Li, 2004: 70) that sustain oppressive cultural and institutional practices that sustain dividing practices that create those who belong and those who do not.

Katherine Runswick-Cole is a highly influential and well-regarded academic in the field of Critical Disability Studies. She is a Senior Research Fellow in Disability Studies and Psychology at the Research Institute for Health and Social Change at Manchester Metropolitan University. As a mother of two young adults, one of whom has been labelled with a learning disability, Katherine’s research has mainly focused on the lives of disabled children and their families and draws on a critical disability studies perspective.

Katherine Runswick-Cole

Verhalen over autisme en inclusie, en erbij horen

In deze presentatie zal Katherine Runswick-Cole vertellen over haar onderzoek in Canada. Thema van dit onderzoek was autisme en inclusie in scholen.

In de scholen werden workshops gehouden. In een workshop werden verhalen opgebouwd. Via film, geluid, beeld, stem, muziek,....liet men de kinderen ‘spreken’. Het project onderzocht hoe dit inclusie kan versterken. De filmpjes en de workshops maakten ruimte voor een andere kijk op verschillend-zijn, op autisme en inclusie. Er werd zo ruimte gemaakt om na te denken over ‘erbij horen’ en ‘geborgenheid’.

Trudy Dehue

Suppose it will be normal to be different

If we define characteristic X (say lack of attention) as mental disorder Y (say ADHD) it isn't biology that tells us to do so. Rather it is a matter of framing X as something to be corrected by mental health care. This may be a helpful way of handling particular human characteristics. However, often a remarkable reversion takes place.

In everyday life, in magazines and newspapers and even in the heart of science, we are being told that disorder Y 'expresses itself' in characteristic X. It is argued that disorders such as ADHD or Autism can also 'express themselves' in less symptoms or that they typically 'hit' particular people. Trudy Dehue discuss this so-called reification of definitions as a maybe understandable but also quite consequential habit. What will happen if it becomes normal to be different again?

Trudy Dehue first graduated in Psychology and next also in Philosophy. She gained her PhD thesis on historical changes in the meaning of the concept of 'science'. From 1995 until her obligatory retirement because of age she worked as a full professor at the University of Groningen. Her most acclaimed publication is entitled: 'De depressie-epidemie. Over de plicht het lot in eigen hand te nemen' [The depression epidemic. On the duty to manage one's destiny]. In this book, Dehue studies the changing meaning of the notion of 'depression' and its individual as well as social consequences. It won the Eureka prize and was named by NRC newspaper as one of the 10 best international non-fiction books of the first decade of this century. Trudy is currently a sought after speaker in and outside the academic field.

Trudy Dehue

Stel je voor dat het normaal was om anders te zijn

Als we 'aandachtstekort' benoemen als 'ADHD', dan is dat een afspraak. Dan betekent dit ook dat we dit als een probleem zien, dat moet worden verholpen met gezondheidszorg. Het lijkt ons helpend om zo naar menselijke eigenschappen te kijken.

Maar we zien in onze samenleving iets anders… We draaien het om. Ons wordt verteld (in tijdschriften, in de krant,...) dat 'ADHD' zicht toont in 'een aandachtstekortstoornis'. Alsof 'ADHD' iets biologisch is: dat toeslaat en omschreven kan worden in vastgelegde eigenschappen.

Trudy Dehue stelt ons de vraag: Wat zou er gebeuren als het normaal wordt om verschillend te zijn?

Michael Stein

The first and second decades of the CRPD

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by consensus on December 13, 2006, and went into operation on May 3, 2008. This talk takes stock of the progress and success of the CRPD's first decade, as well as the shortcomings and unmet opportunities of the treaty. It then offers reflections on some of the challenges that lie ahead for the next decade. In doing so, I mean to provoke discussion surrounding what steps must be taken, and what hurdles overcome, to continue the CRPD's agenda of deep social reconstruction.

Michael Stein is an internationally acclaimed expert on disability law and policy and holds a J.D. from Harvard Law School and a Ph.D. from Cambridge University. He is the Co-founder and Executive Director of the Harvard Law School Project on Disability, as well as Extraordinary Professor, University of Pretoria Faculty of Law, Centre for Human Rights. Stein participated in the drafting of the United Nations Convention on the Rights of Persons with Disabilities, works with disabled persons organizations around the world, actively consults with international governments on their disability laws and policies, and advises a number of United Nations bodies.

Michael Stein

De beginjaren en toekomst van het VN-verdrag inzake de rechten van personen met een beperking

Het VN-verdrag inzake de rechten van personen met een beperking zag het licht op 13 december 2006. Het verdrag ging in werking op 3 mei 2008. Michael Stein brengt rapport uit over de voortgang en het succes van het verdrag gedurende de eerste 10 jaren. Hij werpt ook licht op de tekortkomingen en de gemiste kansen van het verdrag. Dit brengt hem bij reflecties over de uitdagingen die voor ons liggen voor de volgende jaren. Dit levert voer op voor discussie over keuzes en welke stappen moeten genomen worden. Welke drempels moeten overwonnen worden opdat het doel van het VN-verdrag steeds meer in werkelijkheid wordt gebracht: stevige en grondige sociale wederopbouw.

Geert Van Hove

The Art of Belonging: the Conference itself as a site for participatory research

Geert Van Hove will try to use the conference itself as a site of research about ‘belonging’. He offers a first report during this keynote lecture.
As research methodology I will make use of the concepts ‘bricolage’ – ‘diffractive analysis’ and ‘assemblage’.

“Pour le bricoleur, écrit Lévi-Strauss, « la règle de son jeu est de toujours s’arranger avec les “moyens du bord”, c’est-à- dire un ensemble à chaque instant fini d’outils et de matériaux, hétéroclites au surplus, parce que la composition de l’ensemble n’est pas en rapport avec le projet du moment, ni d’ailleurs avec aucun projet particulier, mais est le résultat contingent de toutes les occasions qui se sont présentées de renouveler ou d’enrichir le stock, ou de l’entretenir avec les résidus de constructions et de destructions antérieures.” (Lévi-Strauss, Cl., La Pensée sauvage (1962), Paris)

Following Bozalek en Zembylas (2016) : ...A diffractive reading of data goes against interpretivism, as ‘interpretation in reflexive analysis is about reflecting sameness (as in mirroring), or identifying differences from something previously identified and acknowledged’ a thing, an identity, a category, a discursive theme or a subject position’ (Lenz Taguchi, 2012, p. 269). Difference in interpretivism is grounded in an ontological essentialism between identified categories (man/woman, working class/middle class, white/black, etc.). Rather, a diffractive analysis views difference as a RELATIONAL ONTOLOGY, that is, an effect of connections and relations within and between different bodies, affecting other bodies and being affected by them (Lenz Taguchi, 2012). Diffraction can then be regarded as an ethical and socially just practice, in that it does not do epistemological damage, pitting one theory/position/stance against another, but carefully and attentively doing justice to a detailed reading of the intra- actions of different viewpoints and how they build upon or differ from each other to make new and creative visions...

And an assemblage can be seen as ‘a whole made up from heterogeneous and self- subsistent parts (human and non-human, material or nonmaterial) that gains meaning by being assembled in specific ways’. (Delanda in Schoepfer and Paisiou, 2015)

Prof. dr. Geert Van Hove has been professor in Disability Studies and ‘Inclusief Onderwijs’ (Inclusive Education) at the University of Ghent, department of Special Education since 1993. In the 80’s he started several projects, as one of the first researchers in Belgium, for people with intellectual disabilities. Since 2013, he is appointed as professor by special appointment in Disability Studies, at the VUmc Department of Medical Humanities and within the EMGO+ Institute in Amsterdam. His work specifically focuses on linking practice and academia within the field of Disability Studies.

Geert Van Hove

The Art of Belonging: Het congres als een plek voor participatief onderzoek

Geert Van Hove wil het congres gebruiken als onderzoeksplek en brengt ons het verslag van zijn onderzoek. Zijn onderzoeksmethode is uit te leggen met deze drie woorden: ‘bricolage’, ‘diffractieve analyse’ en ‘assemblage’. We proberen deze termen hier helder uit te leggen.

‘Bricolage’: De kunstenaar/knutselaar/bricoleur bouwt met gereedschappen en materialen een constructie. Hierbij komt de bricoleur voor problemen te staan. Hij moet dingen gaan oplossen, zich aanpassen aan omstandigheden,... Hoe gaan wij om met nieuwe situaties? Je bedenkt toch niet altijd gloednieuwe oplossingen? Wat je al kent en wat je al hebt, ga je aanpassen...

‘Diffractieve analyse’: Onderzoeksresultaten kunnen op verschillende manieren geordend en geanalyseerd worden.

Bij diffractieve analyse gaat het niet om resultaten in hokjes plaatsen maar het verbinden en verweven. Hierdoor ontstaan verrassende patronen en andere kennis. We gaan op die manier mensen niet indelen in jong of oud maar relaties zoeken tussen beide. Het ene staat niet meer tegenover het andere. De onderzoeker gaat aandachtig het verschil in de resultaten onderzoeken zonder uit elkaar te trekken wat misschien wel op verschillende manieren is verbonden.

‘Assemblage’ in de kunstwereld betekent dat voorwerpen bedachtzaam worden bij elkaar gebracht waardoor nieuwe kunstwerken ontstaan.
De term ‘assemblage’ wordt ook gebruikt in andere ‘werelden’. Ook in die van het onderzoek. Dit congres is bij voorbeeld een voorbeeld van een assemblage van heel verschillende op zichzelf bestaande mensen, met eigen taal, met voorwerpen en materialen, met gedrag en bewegingen… Door mensen en dingen samen te brengen op een bepaalde manier, krijg je een nieuw geheel dat nieuwe betekenis verwerft...

Alex Naber and Ans van Berkum

Alex Naber draws, paints and writes poetry. He fills dummy's with poetry about important questions such as: 'what is love?', 'How do you flirt with someone?' or 'what happens when we kiss?' He investigates such themes by means of lists and schedules. Also, he writes stories for movies in which he is the main character, supervisors help him during the progress. In these movies, he runs around as a feminine public favourite, dangerous criminal, vamp or simply as girl. He joins auditions and performs as actor in theatre and on television. He dances, makes up a movie with many famous actress... Step by step he conquers the stage where people look at him, applaud for him and smile at him. That's where Alex Naber is in the spotlights, that's where he is happy.

In his art he sketches short periods in which he conducts theme›s like creepers, Egypt and the musical, but there is only one that will never stop: that of the woman. It›s a never ending story. One might call his method obsessive, mainly because his work mostly comes in series. On little paintings with pink background, many ladies flutter around in black suit that leaves the bottom and breasts uncovered. The breasts get piercing, bright red nipples and the ladies are sniffing each others Bottoms. Some of the women even fart, showing his fantasy literally knows no boundaries.

The Original way in which Alex Naber gives life to his fascinations, leaves many young artists flabbergasted. Such freedom is rarely seen in art and leaves many fellow artists in awe. Alex has Down syndrome and that seems to help him to shape his greatest fascination: the woman. A sweet creature that's kind, looks at you and caresses. The creature who has a vagina and can make you lose control. "I want to make love to a woman. i want to have breasts", goes one of his poems. His fascination now turns inwards and causes a stronger feminine feeling. His longing he transforms into a new persona: "Alex is a girl's name", he entrusts me.

Alex is his body. That's the instrument of his artistic discoveries and representations. He is completely entangled with it, as with his emotions. He does not look at other art, though he does relate to the world of film, theatre and television; all in which fame is at hand. Alex knows no shame. What you see is what you get. His art knows many forms, is rich and as deep as his personality.

Alex is a girl's name is a book about his life as an artist, about his work that mesmerizes many people by the autonomy it represents. For Alex Naber it's all about the question "Who am i?" Am I a woman with a bottom and breasts in a silky nightgown? A man with a lot of feminine traits, who likes to be in the centre of attention? The lonely dreamer who reaches out? In any case he's a man with Down, who grabbed all opportunities our community has to offer. His talent is a gift to the world. The book places his art in context of his sources, personal background and culture, and emphasizes the relationships with Outsider Art. Photographer Marco Bakker portraited the artist, dressed in several outfits that accentuate his inner identity.

Alex Naber en Ans van Berkum

Alex Naber tekent en schildert. Hij schrijft gedichten. Hij vult dummy's met zijn gedachten over belangrijke vragen als 'wat is liefde?', 'hoe moet je iemand versieren?', of 'wat gebeurt er bij zoenen?', thema's die hij heel precies onderzoekt in de vorm van lijsten en schema's. Hij bedenkt verhalen voor films waarin hij zelf de hoofdrol speelt en die hij uitvoert met begeleiders. Daarin dartelt hij rond als vrouwelijke publiekslieveling, gevaarlijke boef, vamp of gewoon als girl. Hij doet audities en treedt op als acteur in theater- en televisiestukken. Hij danst. Hij bedenkt een film met veel bekende actrices. Stap voor stap verovert hij het podium waar mensen naar hem kijken, voor hem applaudisseren en hem toelachen. Daar staat Alex Naber in de spotlights, daar is hij gelukkig.

In zijn beeldend werk tekenen zich korte periodes af waarin hij aan thema's werkt als griezels, Egypte en de musical. Maar één lijn blijft altijd doorgaan: die van de vrouw. Dat onderwerp raakt nooit uitgeput. Zijn aanpak zou je bijna obsessief kunnen noemen, ook omdat het werk vaak in series verschijnt. Op schilderijtjes met een roze achtergrond tuimelt de ene na de andere dame in het rond, in een zwart pakje dat haar billen en borsten bloot laat. Borsten krijgen uitstekende vuurrode tepels. Billen worden besnuffeld. De een bij een ander en die ander weer bij een ander. Borsten groeien tot reusachtige proporties of krijgen een gezicht. De poses waarin hij vrouwen schildert die scheten laten, tonen dat zijn fantasie werkelijk geen grenzen kent.

De volstrekt originele manier waarop Alex Naber zijn fascinaties verbeeldt, doet de monden van jonge kunstenaars open vallen. Zo'n vrijheid wordt in de kunst zelden waargenomen, al zijn er veel collega's die er intens naar verlangen. Alex heeft een syndroom van Down en dat helpt hem blijkbaar om volstrekt onbeschroomd te verbeelden wat hem interesseert. De vrouw dus. Die lief is, die je aankijkt, je streelt. Die een vagina heeft. De vrouw waarin je op kunt gaan. "Ik wil met dame vrijen. Ik wil hebben krijgen tieten", dicht hij. Zijn fascinatie keert zich naar binnen en veroorzaakt een almaar sterker vrouw-gevoel. Zijn verlangen zet hij om in een nieuw personage. "Alex is een meisjesnaam", vertrouwt hij me toe.

Alex is zijn lichaam. Dat is het instrument van zijn artistieke ontdekkingen en representaties. Hij valt er volledig mee samen, net als met zijn emoties. Hij kijkt niet naar andere kunst, al verhoudt hij zich wel tot de wereld van film, theater en tv, waarin roem regeert. Alex kent in eerste instantie geen gêne. Wat we zien is zijn rauwe zelf. Zijn kunst in al zijn vormen, is rijk en diep als de mens die hij is.
Alex is een meisjesnaam is een boek over zijn kunstenaarschap. Over zijn werk dat velen verwondert door de autonome kracht die het uitstraalt. Het gaat Alex Naber om de vraag wie hij zelf is. Een vrouw met billen en borsten in een tafzijden japon? Een man met veel vrouwelijks, die graag de ogen van anderen op zich gevestigd ziet? Een eenzame dromer die naar de ander reikt? In elk geval een man met Down, die alle mogelijkheden tot ontwikkeling kon aangrijpen die onze maatschappij mensen als hij te bieden heeft. Zijn talent is een gift aan de wereld.

Het boek plaatst zijn kunst in de context van zijn bronnen, persoonlijke achtergrond en cultuur, en legt verbanden met Outsider Art. Fotograaf Marco Bakker portretteerde de kunstenaar, gekleed in de verschillende outfits waarmee hij zijn innerlijke identiteit accentueert.

Abstracts poster presentations

P – 1

The experience of body awareness in people with Multiple Sclerosis and people with a chronic lung disease

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Aim
This study focuses upon how people with MS and a chronic lung disease experience 'body awareness' in daily life from a phenomenological perspective in relation to their well-being.

Methods
Open interviews and focus groups are being used to elicit the lived experiences of people with MS and a chronic lung disease concerning their body in daily life.

Results
We are currently interviewing people and we have no results yet. However, we will have (preliminary) results by the time of the conference.

P – 2

The Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities: Necessity and Implication beyond Disability Discrimination Act

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Aim
The Korean Parliament stated that health services would be covered by the Disability Discrimination Act 2007. However, when people with disabilities (PWD) are at their most vulnerable, for example when in hospital or subject to medical procedures, the antidiscrimination law fails them. In Korea, the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities (Disability Health Act) was enacted in 2015. We aim to analysis the gap of health outcomes between PWD and those without disabilities and to evaluate the necessity and implication of this act beyond the antidiscrimination law.

Methods
In Korea National Health Insurance (NHI) covers almost the entire Korean population and National Disability Registry (NDR) covers those with disabilities more than 90%. Using NHI claims data and NDR, we compared health behavior, cancer screening rate and mortality between PWD and those without disabilities. And then, we overviewed the Disability Health Act and evaluated the necessity and implication of this law.

Results
Compared to people without disabilities, PWD had a higher risk of depression, caries, fall, fracture, suicide risk, with adjusted odds ratio (AOR) of 1.58, 2.90, 1.71, 1.26, 1.95, respectively. PWD went to hospitals in more advanced cancer stage, and therefore death risk was 1.14 times higher than those without disabilities (95% confidence interval [CI], 1.13-1.15). Despite the health inequalities of the PWD, there were many difficulties in resolving the discriminative factors due to the specialization and specialty of the medical field. Accordingly, the Disability Health Act was enacted in 2015. This law mainly included responsibility of government and local state, the program for health screening, health care, and health promotion, respectively, accessibility to medical care, health education and the right to health.

Conclusions
People with disabilities encounter a range of barriers when they attempt to access health care services. Additional legislation focused on health care needs of people with disabilities will accelerate health care improvement of PWD where political will, funding, and technical support accompany implementation.

P – 3

Health policy suggestions from disability to possibility in medical education

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Aim

Despite the fact that concerns related to doctors with disabilities have been growing and reported in media, it has not been properly addressed so far. I aim to propose a number of suggestions from the health policy point of view, in addition to my perspective of medical education.

Methods

I have had a rare congenital degenerative retinal disease. In the childhood, I often had to stop playing and come home when the day got dark as it became difficult to identify objects. I applied to medical school with a determination to treat my eyes that are different from others. However, a rare degenerative retinal disease, one that I have, was not treatable. I strove to endure and overcome the situation I was in to live a life that is dedicated for others who are similar to me. Currently, I do not perform medical treatment but engage in research, education, and social activities using reading devices and screen readers. However, education for doctors with disabilities in Korean and many developing countries is rather inadequate compared to the other developed countries.

Results

First, there needs additional legislation to solve this problem. Second, assistive technology that is user-friendly for doctors with disabilities should be provided to physicians with disabilities. Third, we could give benefit to the hospital if it voluntarily trains disability doctors. Fourth, public medical practitioner T / O is to be established in public hospitals that have national characteristics. Fifth, in accordance with the Anti-Discrimination Act for Persons with Disabilities, it is necessary to educate hospitals that make such announcements on sanctions or disability susceptibility through consistent monitoring.

Conclusions

There are still great deals of obstacles in the training of people with disabilities. In the mean time I realized that there are a lot of physicians with disabilities who are better educated than me, do not work, are isolated from the rest of the world. If they were given a chance, they would have been a better medical doctor than I am.

P – 4

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Aim

Exploration of innovative ways for the inclusion of children with disabilities inside a facility that presents a unique opportunity – a kindergarten for children with special needs alongside another for mainstream education.

Methods

Seventy seven children aged 3-6y from all kindergartens participate in the pilot. This presentation will focus on two types of inclusion: Inclusion of children with disabilities-as a group-in the inclusive kindergarten, and reverse inclusion in which a group of children from the mainstream kindergarten are included in the DS kindergarten in pre-scheduled activities. In those ways, children with disabilities take part in two groups of belonging: a group of peers with similar disabilities and a group of their peers from the mainstream kindergarten. A designated staff member mediates in the social and educational interactions while providing space for independence to the included children. The minutes of interaction between children with and without disabilities are a measurable indicator for evaluating this process. In addition, at the end of the pilot year, the parental satisfaction and attitudes from the two kindergartens will be evaluated regarding the inclusion.

Results & Conclusions

Shalva offers a unique process of inclusion of children with disabilities in various ways in order to strengthen their belonging to the community and society. The constant increase in the minutes of interaction between children with and without disabilities indicates a dynamic process of socialization and inclusion.

P – 5

Sustainability, Access, and Retention for Students with Disabilities in Kenya

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Aim
This unique study aims to build awareness among key University of Nairobi administrators around how to support and create and maintain a sense of belonging and inclusive learning environments in college classrooms for all students. Recommendations from a focus group are presented and implications for pedagogical and institutional transformation are discussed.

Methods
This study draws from Evans's (2008) five models of disability that continue to dominate the literature today: (a) medical model, (b) functional limitations model, (c) minority group paradigm, (d) social construction model, and (e) social justice perspective. Each of these models as well as Inclusive Education, Universal Design, and Universal Instructional Design had significance in interpreting the results of this research.

P – 6

Friends! Social participation for all students at The Hague University

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Aim
Design a contemporary and personalized support model “Friends” for students with and without a study limitation within THUAS.

Methods
A ‘hands on’ project, inviting students with and without disabilities (n=30) to start with 3 workshops (self-confidence, working together and creativity), scaffolding self-knowledge, an open and social attitude and coping skills. Participants subsequently create a community, become more aware of who they are, their role and responsibility in meeting each other, learning what social networks are important and what empowers you as a person and as a future professional. Students for Students, a kind of ‘market place’ with question and answer, give and take, coach and be coached on studying at THUAS, how to survive major changes and challenges in your age group and how to participate in social situations during and after your study . Former participants and 2 lecturers are present for team building, consult or teaching.

Results
After a first pilot the project will start Oktober 2017.

P – 7

Preliminary evaluation of a self-management training for people with intellectual disabilities

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Aim
To help people with intellectual disabilities (ID) lead an independent life, it is important to promote their self-management. Therefore, in the present

study the effectiveness of a tailored goal-directed self-management training for people with ID will be evaluated. It is hypothesized that the training leads to improvements in independence, support needs, behaviour, quality of life, and self-worth.

Methods

Adult clients with mostly mild to moderate ID, living within a residential setting, enter a weekly training program. During their training they work on self-selected training goals under the supervision of support staff. Questionnaires addressing independence, support needs, behaviour, quality of life, and self-worth are collected 3-6 months before the training program, at the start of the program and 3, 6, 9 and 12 months later. Data will be analyzed with within-subjects analyses.

Results

The evaluation of the training program is still in progress. The first results suggest that the training effectively contributes to the achievement of goals in the domain of self-management.

Conclusions

The results of this study will show whether the tailored goal-directed self-management training increases the level of independence of people with ID, with secondary improvements in support needs, behaviour, quality of life and self-worth.

P – 8

Promoting independence in people with intellectual disabilities: Results from a focus group study

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Aim

People with intellectual disabilities (ID) often struggle with independently handling their own affairs in daily life. Being independent is however regarded as important by people with ID, and has been related to increased levels of happiness, community participation, and quality of life. Therefore, promoting the level of independence of people with ID is important. This focus group study concentrated on the concept of independence, just as its (dis)advantages, the requirements for increasing independence in people with ID, currently experienced barriers and possible solutions.

Methods

Seven focus groups with either self-advocates with ID (n=7), support staff (n=17), or legal representatives (n=13) were conducted. The self-advocates had borderline to mild ID. The staff members and legal representatives were all supporting adults with mild to moderate ID, living withina residential setting. Various aspects of independence of people with ID were discussed. Verbatim transcripts were analyzed qualitatively.

Results

The analysis of the focus groups with self-advocates is still in progress. According to support staff and legal representatives, people with ID have the ability and the desire to become more independent. A greater independence could lead to improvements in self-worth, mood, and behaviour. When promoting independence in this population, several risks and barriers need to be taken into account. Furthermore, more support and time for people with ID seems necessary, next to a step-by-step tailored approach and good communication between all involved parties.

Conclusions

There is a demand for promoting independence in people with ID. Therefore, interventions need to be developed that are tailored to the needs and (dis)abilities of people with ID. A stepwise approach and good communication between all people involved are also essential.

P – 9

The Grief-Cube©: a tool to support people with ID in their grief

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Aim

People with ID grieve a loss like everyone else. They grieve because someone dies. Or because they become older or handicapped.
Or because they lose their homes. Staff has to help them. But staff often find it difficult how to help. In this research a tool is constructed that helps staff to support people with ID in their grief. This tool is called the Grief-Cube©.

Methods

The Grief-Cube© is based on theory. Now we want to know how it works in practice. Therefore we do three case studies. The support worker talks with a researcher. They make a plan. The support worker talks with the person with ID about his or her grief. The support worker fills in questionnaires. The researcher wants to know if the Grief-Cube© helps the support worker and the person with ID.

Results

We want to know what questions the support worker has about providing grief support. We want to know how confident he is about providing grief support. We want to know how he acts in providing grief support. We want to know what he thinks of working with the Grief-Cube©.
We also want to know what the person with ID thinks about the Grief-Cube©.

Conclusions

The Grief-Cube© can help staff to provide grief support to people with ID.
In this research we find out what is the best way to use the Grief-Cube©.

P – 10

Recognition and the role of family in belonging, being and becoming in Uganda

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Education. Based in Kampala, Uganda

Methods

In this study we interviewed family members of children with neuro-disabilities in Uganda about belonging.

Results

Our findings show how belonging to a family is the starting point of being. Without recognition of the child by the paternal family a child is not given a name, and is not recognized as a member of the clan. Recognition is of life importance in a country where a child solely depends on family members for care; implementation of governmental child protection and child care legislations is lacking. When children with disabilities are seen as part of the ‘we’ the ubuntu concept enables care, support, and inclusion. When this is absent, family members either choose to accept exclusion from the social category (and the child often dies) or fight for recognition and belonging through showing daily that they individually have recognized their child and would like others to consider to do the same. They do not accept the role of autonomous, repressed subject. Parents and siblings in our study felt supported in seeking recognition when meeting with other families in community based rehabilitation networks, and family led community based groups.

Conclusions

We argue for more family led initiatives and support and propose a theoretical framework with starts with belonging, followed by being, and becoming. Belonging in this framework is closely tied to recognition, whilst being is about interdependency between the child and family and community members enabling the child to become.

P – 11

Working together, learning together

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Aim

The aim of the Dutch National Program of Disabilities (NPD) is ‘contributing scientific knowledge towards the full – and fulfilling – societal participation of those with a handicap or chronic illness’ (www.zonmw.nl). With this program, the funding body ZonMw strives to develop, disseminate and applicate knowledge to improve the quality of care for people with intellectual disabilities (ID). In

striving to further the participation and inclusion of people with ID their involvement in the execution of this program is essential. Therefore, people with and without ID will collaborate in research projects receiving a grant from the NPD. As requested by the funding body ZonMW, the aim of this study ‘Working together, learning together’ is to explore the effectiveness of this collaboration between people with and without disabilities on both the project level (e.g., with regard to implementation of project results) and the individual level (e.g., feelings of inclusion and participation). This project builds on previously conducted projects in which we explored competencies considered important in the collaboration between people with and without ID and participatory research methods.

Methods

This study consists of two research components (A and B). Part A consists of action research conducted by a researcher with and a researcher without ID with the aim to equip the members of the different projects with and without ID who received a NPD grant to adequately work together. In part B, interviews will be conducted with these project members with and without ID based on the capability approach. Beside questionnaires will be administered to examine the impact of the collaboration of the project members on participation and inclusion. Assessment will take place in line with the different phases of research (e.g., data collection). In addition, the training offered in part A is evaluated.

Results

The results of this project will be training and coaching materials designed for doing participative research in which people with and without disabilities work together. Besides, this project will give insight in effective ways of collaboration between people with and without ID in research projects, enhancing inclusion and participation.

Abstracts oral presentations

Stream: Representation & Stigma

O – 1

Do Deaf and hard-of- hearing people belong to each other? Issues of identity and in-group discrimination.

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[1] University of Utrecht, Utrecht, the Netherlands
[2] GGMD, Gouda, the Netherlands

Aim

The aim of this study is to explore a well-known fact within the group of people with limited or no hearing, that is: the often negative attitude of deaf people and people who are hard-of- hearing towards the other group. Both groups go into all efforts to make clear that they do not belong to each other. As far as we know, this phenomenon has not been studied and it is thus not clear how it can be explained. Does it have to do with range of hearing loss, or chosen language (sign language or spoken language), type of education or social attitudes? There's a lot of research regarding to social theories and social processes, but as far we know, those theories have not been applied yet to deaf and hard-of-hearing people. In this study we will apply social theories on these two groups to see if, and how these theories can explain the attitudes of deaf and hard-of- hearing people towards each other.

Methods

An extensive literature review has been conducted, resulting to a number of key factors. A survey questionnaire, for deaf and hard-of- hearing individuals, is being developed, using the key factors that have been found. The result will be an online survey that is available from May to June 2017.

Results

The results will be known after June 2017.

Conclusions

We can not give any conclusions yet. Our hypothesis is that hard-of-hearing people have a more positive attitude towards their own group than towards the deaf outgroup, and vice versa. We also expect that this effect is explained by what each group considers prototypical and the chosen language: sign language or spoken language. We expect that people who identify themselves stronger with the ingroup, will have more negative attitudes towards the outgroup.

O – 2

Combatting Stigma on mental illnesses: what works?

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Samen Sterk zonder Stigma, Amersfoort, the Netherlands

Aims

Mental health problems can be hard for anyone to cope with but it can be made worse by having to deal with stigma and discrimination from others who are not equipped with the facts.
Many people will not seek support due to the stigma they expect to face and the self stigma of feeling a burden. No one should ever be made to feel ashamed or embarrassed to tell anyone that they experience mental health problems. Together, we have a shared responsibility to understand what mental health stigma and discrimination feels like and drive home the message that everyone is entitled to and deserving of help and support. To stigmatise and discriminate is to mark someone as different.

Methods

By far most western countries have been executing programs fighting stigma, run by the government or other by other initiatives. They all experienced that there is not one sole solution to combat stigma. There are factors for success. In The Netherlands Together Strong without Stigma is working on changing societal behaviour towards people with mental health problems. We chose an integrated approach, which is based on the success factors of interventions from both abroad and other emancipation movements.
In this presentation we will tell which success factors work and how stigma is combatted at in The Netherlands.

O – 3

The SARI Project: a randomised controlled trial of interventions to reduce stigma in Cirebon, Indonesia

Wim van Brakel, Ruth Peters, Dadun, Mimi Lusli, Marjolein Zweekhorst, Joske Bunders, Irwanto
Netherlands Leprosy Relief, Formerly Disability Studies in Nederland, Amsterdam, the Netherlands

Aim

Stigma is one of the important factors leading to social exclusion for people with disabilities. Persons affected by leprosy and their family members are often stigmatised and experience problems in social participation. Their sense of belonging may be severely affected.
The SARI Project in Cirebon, Indonesia, aimed to test and evaluate three intervention strategies, peer counselling, socio-economic development (SED) and contact between community and affected persons, to reduce stigma against persons affected by leprosy and thus improve their belonging in family and society.

Methods

This study used a controlled trial design in which pairs of the stigma reduction interventions were randomly allocated to sub-districts in Cirebon. The study sample comprised community members and persons affected by leprosy. Mixed methods were used to establish a baseline regarding stigma and related parameters, to monitor the implementation and assess the impact of the contact events. Among community members, attitudes and expected behaviour were measured using the EMIC stigma scale and Social Distance Scale (SDS). Among leprosy-affected persons, the SARI Stigma Scale assessed anticipated, experienced and internalised stigma.

Results

Two independent representative samples were drawn from community members in the study area. The baseline sample included 213 persons; the final survey 402 persons. A highly significant reduction in stigma scores was found in intervention areas where contact events were organised, while differences in other areas were not significant.
The largest differences were found among those attending actual contact events. Among affected persons, 237 had complete records in both baseline and final surveys. Among them, stigma levels had also reduced significantly and restrictions in social participation decreased.

Conclusions

Contact with affected persons, peer counselling and SED are effective interventions to reduce social stigma in the community and its impact on persons affected by leprosy. Many had developed a new sense of belonging in their family or community. The interventions can be easily adapted for use with persons with other NTDs or disabilities.

O – 4

Disability on Display: New Approaches in European Medical Museums

Manon Parry
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Aim

Museums can play an important role in society by contributing to health, wellbeing, and social inclusion. Moreover, European governments are increasingly turning to these cultural institutions to undertake such work, in response to aging populations and declining budgets for social welfare. Following extensive work in the UK, art galleries and museums in the Netherlands and elsewhere are introducing new programs for visitors with disabilities, and developing more accessible projects, with a broader relevance for diverse communities.
Medical museums should be at the forefront of this work, as they hold special potential to address topics of great significance, from illness, caregiving, and disability, to gender, fertility, and sexuality; from bodily difference to mental health. However, because their collections of historical objects and images usually represent the perspectives of medical practitioners and not the people they studied and treated, curators must work creatively to address the assumptions and silences their museums contain. These museums often also struggle with the expense of maintaining fragile and decaying collections, and with disagreements between staff over the most “appropriate” audiences for exhibitions of human remains and medical tools.
Nonetheless, some medical museums are reimagining the stories they can tell and the communities they can speak to. Museums of the

history of psychiatry, for example, are shifting their activities to take on new identities as “museums of the mind,” with a wider framework for discussing mental health in terms of social, as well as biological, processes. Other medical museums are addressing the limits of the medical model of disability, as well as the role of science in narrowly defining norms, and stigmatising bodies and behaviours that deviate from them.

Methods

As part of a larger project investigating the exhibitions strategies of medical museums across Europe, in this presentation I will focus on new approaches to the representation of disability in museums, drawing on examples from the UK as well as new projects in development in Spain and France. I will show some of the images and ideas being used, and engage the audience and fellow presenters in a discussion of the limitations and the potential.

O – 5

To see or not to see: exhibition experience from the perspective of wheelchair users

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Aim

This ongoing research is looking into the way wheelchair users choose their position within an exhibition. With the UN treaty for the rights of disabled people being ratified in The Netherlands in 2016, more and more museums are making themselves accessible. But access is not inclusion. A whole world lies behind ramps and bathroom handlebars. The focus of this research is on the way wheelchair users perceive their position within an exhibition. By paying attention to the interaction between the participant, the artworks, and the wheelchair they use, this research attempts to foster a broader understanding of their exhibition experience.

Methods

For this research project, nine wheelchair users have been invited to visit a modern art exhibition in a museum in The Netherlands. They are wearing video glasses to record head movements. A GoPro camera is attached to the wheelchair to create a visual overview of the visit. The video footage gives an opportunity to look through the eyes of the participants. In interviews, this visit is discussed and compared to visitors’ previous museum experiences. By looking at fragments from the video, questions are asked about choices in positioning within the exhibition and in front of the artworks. How do participants choose, when do they choose, and why do they choose?

Results & Conclusions

Results so far reveal that the wheelchair as a mediator holds a key role. It is a physical enabler, but at the same time a social disabler. Without their wheelchair, the participants would not even be in the exhibition at all. At the same time the wheelchair causes a different viewpoint on the artworks that are being displayed. Using a wheelchair sometimes results in a more close and intimate view of the artwork, other times creating distance and exclusion. It is already clear that the data offer a rich insight in the experience wheelchair users have while visiting a museum. This is on several topics; inclusion, social participation, architecture, aesthetics, agency, physical access and digital access. The area of museum experience by wheelchair users seems largely unexplored.

O – 6

Diversifying the Collections: The Intersection of Race and Disability in Museum of the Mind Het Dolhuys

Daniël Korving Elisabeth Hiddinga
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Aim

This paper aims to discuss how, on various levels, Museum of the Mind “Het Dolhuys”, a museum that focuses on mental disability in the Dutch town of Haarlem, has in- and excluded issues of racism and race. It will focus on both the museum’s history and current exhibition and analyze, on the one hand, the in- and exclusion in the museum and its mediations of minority groups within Dutch history and society and, on the other hand, the representation of people of colour in the museum’s historical art, and temporary exhibitions.

Methods
Bringing together theories from disability, critical race/postcolonial and museum studies, this paper uses methods of discursive and visual analysis, as well as curatorial analysis. It will provide steps toward a reflection on the differences, commonalities, crossovers and tensions between disability and critical race studies when brought together in an intersectional museum analysis.

Results & Conclusions
The paper draws attention to a number of important issues concerning the intersection of disability and race in museums:
1. The curatorial challenges in creating a museum that is informed by an intersectional approach (in this case concerning disability and race).
2. The partly overlapping and mutually enabling histories of disability and race in Europe, and how the museum can respond to these histories.
3. The representation and accessibility of the museum to different groups in society.

O – 7

Experience All Inclusive, how simulations have a positive effect on stigma

Martine Baadenhuijsen
All Inclusive at Work, Utrecht, the Netherlands

Aim & Methods
We provide simulations that offer an alternative view on people with disabilities . In these
simulations one can experience first-hand that anybody possesses certain skills and talents
and that having a disability requires specials skills and creativity.
At the moment we focus on professional organisations in order to show them the added value of employees with disabilities. Since it is impossible to imitate the 24/7 effect of having a disability, we aim to show the effects of disabilities in a work environment.

Results & Conclusions
Our workshops have a big impact on the participants. Besides a unique experience we share the learning effects of our participants. It does not matter if our participants hardly know any disabled persons or if they are professionals that frequently work with this target group. It´s all about experiencing in order to get a positive mindset towards inclusion.

NL

Ervaren hoe het is om te leven met een beperking
Deze workshop zal je nooit vergeten! Je ervaart hoe het is om te leven en te werken met een beperking. De ervaring neem je mee in de discussie EN in je verdere leven. De bedoeling is om mensen positief te veranderen. De organisatie ‘All Inclusive at Work’ wil zo stappen zetten naar minder stigma en meer inclusie.

O – 8

Card game ‘Screw loose?’ let’s talk about mental health and quality of life!

Marrig van der Werf[1], Gabriëlle Gortworst[2]
[1] Foundation KernKracht, Gouda, the Netherlands
[2] Foundation de Bagagedrager, Drempt, the Netherlands

Aim & Methods
Interactive workshop by experts by experience from Foundation De Bagagedrager and Foundation KernKracht in cooperation with Foundation Samen Sterk Zonder Stigma (SSZS). In this workshop we explain the card game and its various possibilities: Screw Loose? developed by Ellen Spanjers from Foundation ‘De Bagagedrager’.
We play the English version of the card game developed by kernKracht within the European Erasmus + project: Equil. (Improving employment support for people with Mental Health issues) We will talk about mental health, quality of life, recovery, stigma and inclusion. Taboo subjects that people with mental health issues face are being discussed in a low-threshold (easy and comfortable) way. The aim is creating more openness, recognition, understanding and awareness about mental health issues.

Equality is the guiding principle in this workshop The low-threshold (easy and comfortable) approach during the workshop creates a safe situation to discuss many dilemmas, experiences and possible taboos. The workshop leaders are experts by experience and share their own experiences with taboos, stigma and mental health issues.

Playing ‘Screw Loose ?’ breaks taboos

NL

Kaartspel ‘Een steekje los’. Laat ons praten over geestelijke gezondheid en kwaliteit van leven!
Deze workshops wordt geleid door ervaringsdeskundigen van de Stichting De Bagagedrager en KernKracht in samenwerking met de Stichting Samen Sterk Zonder Stigma. Ze leggen het kaartspel ‘Een steekje los’ uit en tonen de verschillende mogelijkheden ervan. Via het kaartspel komen volgende thema’s in het gesprek: geestelijke gezondheid, kwaliteit van leven, herstel, stigma en inclusie. Op een niet-bedreigende manier krijgen mensen de kans om over onderwerpen te praten die vaak in de taboe-sfeer verblijven. Doel van het spel is: meer openheid, erkenning, begrip en bewustzijn over geestelijke gezondheid.

O – 9

Digging tunnels with songs of experiences of the (dis)abled.

Gert Rebergen
Rebergen Consult – Izare, Zutphen, the Netherlands

Aim & Methods
The interpretation of experiential melodies in terms of an empirical design and associated consequences (Dewey) requires differential frames. Experiences of the (dis)abled are flarfy, atopic, impetuous, miraculous, transverse, assembling. A draft collective strategy of experiences will be presented as a temporary grounding of a critical discourse to the benefit of the (dis)abled: a sanctuary for the experiences of (dis)abled. First of all associates construct a theme oriented, (partly) the dominant knowledge tunnelling discourse of experience. Secondly the bridge between different perspectives can be (re)built by actors who want to mediate retaining singularities. (Latour) Gained and expected experiences of the (dis)abled are generally indulged and categorized by scientists and professionals. Scientists produce(d) models for statistic generalizations and outsider models for qualitative interpretations. For example the concept of the system and life-world (Habermas) is especially used to categorize in a positive or negative way the proportions of experiences and systems. But at the end of the day, the songs of experiences (Jay) are really heard and co-decisive and fully applicable in policy-making processes? Why are insider approaches still pretty rare in spite of all the efforts to pay lip services to the (dis)abled? Experiences will be crushed by ‘willing’ and ‘thinking’ (Arendt). Learning experiences of scientists and professionals drive too often and too many wedges between themselves and the (dis)abled. And politicians listen above all to scientific and professional ‘knowledgeable opinions’ presented as knowledge. Unfortunately the songs of experiences don’t sing their own blues. The natural partner of the disabled are the abled, the citizens. Together they are able to set the agenda in scientific, professional and political arenas when consequences of ‘wicked’ topics are threatened or occupied by reliable statistics and outsider models. This presentation is meant for people who love concepting, multilogues, tinkering and carving, beyond addresses, debates, the truth and models.

O – 10

Disability experience through the body of a designer: the case of architect Marta Bordas Eddy

Natalia Pérez Liebergesell, Peter-Willem Vermeersch, Ann Heylighen
KU Leuven, Dept. of Architecture, Research[x]Design, Leuven, Belgium

Aim & Methods
Studies have offered rich insights into how the designed environment is experienced by people with different abilities and conditions. In the context of architectural design, this experience is only starting to become recognized as a valuable resource for designers. Drawing from the premise that disability is a particular kind of experience, we report on an ongoing focused ethnography of architect Marta Bordas Eddy’s design practice. In doing so, we analyze the connection between (a) her design practice and outcomes and (b) her lived (or embodied) experience of needing a wheelchair and the role of architecture therein. We conducted four face-to- face interviews in a contextualized setting, two with the disabled designer, one with her sister/co-worker and one with her life partner/co-habitant, we gathered design documents, and we visited and analyzed the house that she designed for and by herself.

Results & Conclusions

The study highlights how her embodiment of disability in combination with her background has multiple effects: (1) through experiencing dis- and enabling environments and the potential of design therein, she is able to appreciate distinct architectural qualities; (2) she developed the capacity to materialize subjective experiences of her own embodiment in combination with other, more technical requirements into a final built form; (3) it grants her firm a particular kind of distinction and credibility, in addition to a more nuance understanding of accessibility regulations that are linked to her impairment and an insight of the requirements behind them; and (4) the emotional dimension of her embodied cognition makes her aware of both the value of her own lived disability experience in design practice, and her limited knowledge on how other people experience space differently. Her design expertise in combination with disability experience has a positive effect on her impairment, turning it into a rare ability that guides her design practices and outcomes.

O – 11

Disabled images: a quantitative content analysis on disability television representations in Flanders

Susan Vertoont
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Aim

In 2009 Belgium ratified the UN Convention on the Rights of Persons with Disabilities. In article 8, the Convention explicitly calls attention to media imagery of disability, because international research pointed out that disability is often marginalized, stigmatized and stereotyped in media representations. However, the way disability is being represented in Flanders, has almost never been studied before. Therefore, this research aims to measure how often, and in which manner, people with disabilities are represented during prime time television in Flanders.

Methods

By means of a quantitative content analysis we looked into the television context (broadcasters, genres, formats, productions) of disability, the television roles of people with disabilities, and the way disability intersects with other identity categories on screen, like gender, age, ethnicity and sexuality.

Results

Results indicate that disability is still severely underrepresented on Flemish television. However, not only the quantity is problematic, the quality also remains limited. With only a few genres (such as ‘television news’ and ‘soap operas’) and a few roles (such as ‘subject of a portrayal’ or ‘expert by experience’) that include people with disabilities, we still lack coincidental and multidimensional portrayals that tend to normalize disability. Moreover, the inquiry into intersectionality revealed that disability on television almost never intersects with other repressed identities. There were only very few homosexual people or people with a migration background, who had a disability in our sample. We also noticed an overrepresentation of children and young adults, but we did not register any disabled seniors. In addition, traditional gender constructions are maintained within disability representations. Women with disabilities are more frequently represented as victims, and are more related to attitudes of pity, while men on the contrary are mostly superheroes associated with sympathy and respect.

Conclusions

We conclude by stating that the paradigm shift in attitudes and approaches to persons with disability – as described by the UN Convention – is not yet reflected in Flemish television representations. People with disabilities are still not portrayed equally as people without disabilities. Moreover the limited roles, genres, formats, etc. in which they appear, indicate that they still do not entirely belong on the little screen.

O – 12

The Psychiatric Archipelago: Towards an Intersectional Understanding of Psychiatry

Eliah Lüthi
Humboldt University Berlin, Germany and University of Innsbruck, Austria.

Aim & Methods

In this presentation I introduce the concept of the Psychiatric Archipelago, a model of psychiatric areas of influence in interdependency with societal power relations. This concept mainly takes up on two discourses in Mad studies and movements: Works in Mad Studies increasingly highlight the intersectionality of psychiatric influence and sanism with other societal power relations, as example with racism, gender-based discrimination and classism (cf. Diamond 2014; Gorman 2013; Kanani 2011; Kirby 2014; Metzl 2014; Withers 2014). Another field of research and activism discusses the shifting influences of psychiatry due to reforms (cf. Ben-Moshe 2011; Chamberlin 1978; McKnight 1995; Morrison 2009).

These discourses and my perspective as part of (queer) u/s/x-movements are the starting point of the Psychiatric Archipelago.
In this model, I work with the imagery, or metaphor of an islandscape, inspired by Foucault's Carceral Archipelago (1995). The Psychiatric Archipelago understands psychiatry interdependently with intersectional power relations, as a network of different actors, including media representations, diagnostic manuals, social services, the pharma industry, academia, family and more. In my presentation I show, how psychiatric norms are established in different fields, as example through psychiatric and everyday language, medical and media representations, law and diagnostic reforms. This model aims to expose the often inscrutable and complex workings of psychiatric influence and additionally proposes ways to challenge and intervene in psychiatric structures.

O – 13

A Dutch way: building bridges between practice and science with stories on www.patientervaringsverhalen.nl

Coleta Platenkamp
Stichting CCC, Amsterdam, the Netherlands

Aim & Methods
1.Telling about collecting patient stories and the diversity behind the written stories, documentaries, blogs and short written stories.
2. Showing how a diversity of scientific studies can help patients (ao Tronto/Mol/Levinas/ and see:
https://www.patientervaringsverhalen.nl/?pagina=Interviews+en+verslagen
1. in showing their perspectives and world who wasn't that visible
2. understand how the way they live now found their roots in history of a society
3. Show some activities and best practices (Ont.be, VN resolution, Disabilitystudies, patient activities) to build bridges.

O – 14

Autism Matters, Doesn't it? Analyzing the emergent subjectivities in Tistje – an experience blog on autism

Leni van Goidsenhoven
Cultural Studies, Leuven University, Leuven, Belgium

Aim & Methods
In the course of the 21st century the rise in measured prevalence of autism and research into its etiology have been accompanied by much new humanities research, mostly within the field of disability studies. Ever since, our knowledge and understanding of autism, deeply embedded in historical, social, cultural, and discursive contexts, has undergone a remarkable evolution (Nadesan 2005, Verhoeff 2013, Evans 2017).
Fed by the academic research and by unceasing attention from popular culture, there exist an abundance of literature about how the voices of autistic people have influenced the conceptualization of autism (Osteen 2008, Murray 2008, Davidson and Orsini 2013, Savarese 2014, Wexler 2016). But how does 'autism' as a flexible signifier and label influence the conceptualization of subjectivity? Departing from this question and taking up Goodley's (2013) challenge to explore the ways in which poststructuralist research methodologies open up new ways of thinking about encounters with autism, we analyze the online autobiographical narratives of Tistje – a Flemish experience blog on autism since 2008. More precisely we investigate how Tistje in and through his blogging experiments with autism as a categorical difference as well as with autism as becoming-in- the-world- with-others (Shildrick, 2002); how he emerges as an entangled person of which many stories can be told and have to relate to many stories himself. Furthermore, we focus on how he mobilizes online subjectivities and which role the medium (the Internet and computer) plays in all of this.

O – 15

How Stigma affects us: the voice of self-advocates with Intellectual disability

Dana Roth
Beit Issie Shapiro, Ra’anana, Israel

Aim

This study examined the voices of people with intellectual disability (PWIDD) regarding their experience of stigma. The study's approach is collaborative/participatory, PWIDD are research consultants. This approach views people with disabilities as experts of their lives, while the researchers (who are non-disabled) are the ‘technicians’ in charge of planning, collecting, analyzing the data and writing up the results.

Methods

Data was collected via two semi-structured focus groups conducted with self- advocates and was analyzed qualitatively. The following questions were included: ‘Why are people afraid of us and reluctant to interact with us? Why do people think we are stupid? Why can’t people accept us as we are? Why can’t people believe in us? Are we really disabled? Why do people feel pity towards us? Why do people think we need charity? Why do our families and others tell us we cannot do things?’

Results

The consulting committee recognized that stigma was a very intense, difficult, shameful and painful subject. PWIDD experience stigma and respond with avoidance, frustration, pain and sadness. Five themes were identified: emotional impact of stigma; not understanding why stigma occurs and why it is directed towards them; confusion in self- concept and identity; ignoring as a default response when experiencing stigmatic behaviour; and the opportunity provided by self-advocacy.

Conclusions

Participating in the self-advocacy groups strengthened their sense of personal control: ‘I am responsible for myself’; ‘I am aware of my difficulties, but I am equal’; ‘I can explain what is difficult for me, but I still deserve fair treatment’. ‘I can stand on my own… if I see that things are not right I can say something.’; ‘I can say it in a nice polite way that they should treat us nicely and equally’; ‘I feel that I am doing something for myself and not for someone else’; ‘the group gives me the power, I am not afraid to tell people to treat me with a little more respect.

The need to begin self-advocacy and self-representation from a very young age. This will also provide skills to “deal” with stigma based behaviours and increase self-efficacy.

O – 16

NSGK Jongerencoach supports youngsters to attain personal goals and increase self determination

Gigi Dingler
NSGK Jongerencoach (project of NSGK: the Dutch foundation for children with disabilities), Amsterdam, the Netherlands

Aim

NSGK sees a lot of youngsters with disabilities who underperform. For this reason, the foundation has started the project NSGK Jongerencoach in order to encourage them to use their full potential and find their way in society. Volunteer coaches are accompanying youngsters with creating personal future plans and achieving their goals. The aim of coaching is to increase the self-determination of youngsters by taking steps regarding to their self-formulated goals, along with their network.

Methods

NSGK Jongerencoaches work with youngsters on three main questions: Who are you? What do you want in future? How can you realize this? The coaches help youngsters to dream, turn their dreams into realistic future plans and determine the steps that lead to their realization. Then they start working on it together. Whether it's job search, finding a suitable study, social networking, leisure time, etc. The young participants determine what matters to him/her personally. Person Centered Planning (PCP) is the method on which the coaching is based. Visualization and network involvement are important elements in the coaching. PCP is originally created in the US for people with mental disabilities and it turns out to work for all kinds of people who need help to find their way in society.

NSGK Jongerencoach also provides PCP-workshops for organizations. Young people work with the same themes as in the individual coaching and learn a lot from each other. Participants create their own future posters which they present at the end of the workshop series. After these workshops youngsters have the possibility to keep working on their dreams and goals together with an individual coach.

Results & Conclusions
Until now, approximately 30 young people have been coached and there are about 25 workshops provided by NSGK Jongerencoach. As a result, youngsters are making steps in different areas. These results stimulate us to professionalize and to develop a thoughtful evaluation methodology. For the evaluation we will use the instrument of Goal Attainment Scaling and prepare the measurement of self-determination for the youngsters who join the individual coaching process.

In 2018 this project will turn in an independent foundation: FLOOR jongerencoaching “the

floor is yours”.

O – 17

‘I want to go outside at playtime’, children’s perspectives on inclusion in Uganda

Femke Bannink
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Aim
In sub-Saharan Africa Disability Studies have largely focused on adults with and caregivers of children with disabilities (CWD), children’s narratives are absent in most disability literature (Curran & Runswick-Cole, 2014). Inequality, exclusion, and stigma of children with disabilities in Uganda is high. CWD are often excluded from social activities due to negative beliefs and attitudes, the effects of poverty, and environmental barriers (Bannink et al., 2016; Lwanga-Ntale, 2003; Ojok, 2012). Only 9% of the estimated 2.5 million CWD in Uganda attend primary school (UNICEF, 2014). In central Uganda a CWD is often referred to as ‘omwana teyesobola’ – a child who cannot manage himself or herself (Bannink et al, 2015).
This presentation will describe findings from action research with children with spina bifida and hydrocephalus and their non-disabled peers in Uganda. In our study we aim to understand factors which affect belonging of children with both physical and intellectual impairments and their peers, and identify actions which can reduce inequality, exclusion, and stigma.

Methods
In April 2017 ten children with spina bifida and hydrocephalus from Wakiso district, Uganda, will select a peer (a close friend or sibling); both will be asked to make drawings of themselves and theirenvironment and participate in a workshop in May 2017. In this workshop children will describe their current daily activities, experiences, and challenges, starting from their drawings. They will share ideas on changes they would like to see and develop an action plan. The children will present this action plan to their families, teachers, CBR workers, and other key persons. Videos and photos of the presentation and discussions will be made and a list of action points with persons responsible for implementation will be documented. After the workshop children will be asked to monitor and document implementation of the actions by taking photos whilst persons appointed will be asked to keep a log of actions taken. Children will be interviewed about the results using photo narratives between August and October 2017.

O – 18

Do I belong to a collective experience? A duo-ethnographic enquiry into patient experience and representation.

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[2] University of Gent, Gent, Belgium

Aim & Methods

Even though in healthcare, patient experience is considered to be 'the new heart of healthcare leadership', it is questionable whether patient or client experience can truly represent a collective experience of affected persons. What is more, not everybody wants to belong or be explicitly included in a specific (peer) group, the membership of which is considered by many as unfavorable. For instance, whenever the second author – who lives with a spinal cord injury – hears other affected persons as referring to her as a fellow "peer", it makes her feel vulnerable, associating the word with suffering and -coping difficulties and subsequently associating this with weakness.[1]

How then can we democratize the representational sphere of collective patient or client experience (i.e. peer groups), without overlooking the particular experiences of individuals, which are potentially in tension with dominant discourse (cf. Neumann, 1996). Or in other words: How can subjectivity be acknowledged as an important entry point for including alterity in representation?

This paper aims to explore how a duo-ethnography of two (vulnerable) insiders' perspectives on experiencing living with illness and disability might provide such an important entry point. Rather than trying to 'capture' these perspectives or experiences, which could lead to what Guba and Lincoln (1989) have dubbed 'malconstructions' of people's perspectives, we regard duo-ethnography as a mutual endeavour, occurring between people who are ultimately seen as interdependent beings (cf. Niemeijer and Visse, 2016).

Both authors are scholars working in the field of healthcare at a university department and live with a chronic illness or a disability, respectively in the Netherlands and in Belgium. In substance this paper is ultimately a critical endeavor to see if and how particular experiential knowledge can be viewed as representational and credible collective experience of affected persons.

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[1] Note that the Dutch word for "peers" is "lotgenoten", a word that often triggers associations with suffering and illness, connotations which are visible in English translations: "fellow-sufferers", "fellow-patients".

O – 19

Being blind in a sighted world: Exploring experiences, challenging perceptions

Laura Bulk, Marilyn Smith
University of British Columbia, Public Scholars Initiative, Vancouver, Canada

Aim

285 million people globally are marginalized on a daily basis because we are blind/partially blind. We face social isolation, reduced community participation, higher levels of poverty, and extremely low rates of employment. While legal and political action support inclusion, societal misperceptions of blindness remains a major barrier to personal empowerment, including economic independence. This project aims to prompt action and advocacy that will improve quality of life for blind people and build public understanding of blindness.

Methods

Project co-leads, Marilyn Smith (photojournalist and CEO of Act 4), and Laura Yvonne Bulk (blind scholar, occupational therapist, and advocate) are working in collaboration with an international advisory committee to create a fully accessible multimedia platform to promote open exchange:

- blind people and those in our support networks can share life experiences.
- experts (including community members) can contribute blogs about building personal skills, accessing new technologies, action to improve legal, political and social circumstances for the blind.
- the public can ask questions, interact and learn.

A single portal for storytelling and reporting on academic and technical advances creates a link between evidence and real life. The site will profile people from 8-10 countries, exploring the experience of blindness in diverse contexts, celebrating how we defy stereotypes, and exposing stigmas/assumptions that get in our way. In parallel, experts and community members will contribute blogs that facilitate dialogue, knowledge exchange, and resource sharing. A strong social media campaign will keep blindness “in view” on a daily basis.

O – 20

Belonging in the diaspora via affinities for people with disabilities back home: The case of the Congolese diaspora in Belgium

Patrick Devlieger
KU Leuven, Leuven, Belgium

Aim & Methods
The first initiative for setting up support for people with disabilities by Congolese people were undertaken by the end of the 1960s. These initiatives were in competition with the efforts from foreigners which were mostly better funded. The founders of these initiatives were however intimately linked with Belgium through professional training, but also as a drop-back for insecurities that related to instability resulting from political and economic concerns. This has in many cases led to career paths that split between Congo and Belgium, and in split families, of which a part lives in Congo and part in Belgium. I will argue that the founders as well as the 2 nd generation combine a professional attitude towards disabled people with strategies that increase their belonging in the guest country, Belgium. I will illustrate this with the search for support and funding for initiatives for people with disabilities in DR Congo, that incorporate the strategies of making alliances that reinforce belonging in Belgium.

O – 21

Festival Vrolijk (The Happy Festival), a creative cultural celebration in a co-production by people ‘with’ and ‘without’ intellectual disabilities for the city of Gouda

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Reliëf, christelijke vereniging van zorgaanbieders,
Woerden, the Netherlands

Aim
Festival Vrolijk is a cultural festival organized by and together with people with intellectual disabilities. Both in de production as well in the creative process people with and without intellectual disabilities work closely together towards a cultural celebration in which the voice and (critical) perspective of the people involved on celebrating life together is presented in interactive artistic production together with the audience. The aim is to learn from the process of working together, to develop inclusive working methods and inspiration to develop other local cultural art festivals in other places that stimulate meaningful encounters between people with and without intellectual disabilities and exchange of perspectives. Therefore the process is closely observed on video and evaluated with participants.

Methods
The process is monitored and evaluated to learn from this local co-production for the future. Both for a bigger inclusive festival in Gouda, and for the inspiration and development of other festivals in the Netherlands.

Festival Vrolijk
Festival Vrolijk is een cultureel festival (mede) georganiseerd door mensen met een verstandelijke beperking. Mensen met en zonder beperking werken nauw samen en staan samen in voor de organisatie en creatieve ideeen. Het moet een groot feest worden waarbij de stem en de belangen van mensen met een beperking sterk vertegenwoordigd zijn. Het proces van ‘inclusief festivalbouwen’ wordt nauwgezet gevolgd en geëvalueerd zodat er kan geleerd worden. In de toekomst willen we een nog groter festival

organiseren en we willen andere festivals inspireren tot samenwerken met mensen met een beperking van bij het begin!
De workshop wordt op creatieve wijze gegeven en geleid door Nederlandstalige festivalorganisatoren met en zonder verstandelijke beperking.

Results & Conclusions
Not clear yet because the festival itself takes places on the 11 of November in Gouda, the process of production starts in august.

O – 22

“Where are you from?” – Feeling at home in a Dutch nursing home.

Michou Benoist
Freelance researcher, Velp, the Netherlands

Aim & Methods
‘Thuisgevoel’ or ‘feeling at home’ is a buzzword for Dutch eldercare organizations. It has a connotation of aging in place, in your own home – even though living in institutions would suggest the opposite. How do residents of a nursing home, feel at home? Using participatory observation and creative methods such as life stories, I looked for the meaning of “thuisgevoel” for older people in a Dutch nursing home.
In this talk I will go into the importance of ‘the storyline’ in a life story, and the opportunities of creativity and imagination. Also, on a more political level, I will look into the effects of the disappearance of the Dutch nursing home due to budget cuts. The home of my research has sadly been torn down, and residents have been moved to a suburb, away from the city. What does this mean for the residents, the city and the meaning of ‘home’?

Results
The results were unexpected: Asking questions about where people are from, looking at pictures of former homes and sharing the positive memories, turned out to be a way to help residents feel more at home and even regain this feeling of belonging in their present (nursing) home.

NL

Waar voel jij je thuis?
Je thuis voelen… in een rusthuis. Een beladen thema. Hoe ervaren ouderen het leven in een rusthuis? Voelen zij zich thuis?
Via observaties en het maken van levensverhalen heeft onderzoeker Michou Benoist samen met de bewoners nagedacht en gesproken over hoe zij betekenis geven aan het ‘thuisgevoel’. De onderzoeker werkt met verbeelding, dialoog en ‘reizen in je hoofd’ om hier achter te komen.

O – 23

A voice to belong: how people with intellectual disabilities experience participation in their neighbourhood

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[2] Prisma, organisation for people with intellectual disabilities, the Netherlands

Aim & Methods
In the nineties people with intellectual disabilities were supposed to get back in society by living in neighborhoods together with people without disabilities, since every person has the right to be part of the society. The government expected people without disabilities to help people with disabilities to integrate in society. However, until now people with disabilities and people without disabilities have not actually been ‘living and working’ together in Dutch neighborhoods. Prisma, a health care provider in the south of the Netherlands, acknowledges that inclusion of people with intellectual disabilities does not automatically take place and that inclusive initiatives need to be organized first. Therefore, since several years Prisma has been experimenting with a local service center called ‘the Red Carpet’ in Kaatsheuvel. This center is run for ánd by people with intellectual disabilities and all others living in the neighbourhood. Every day this center is visited by people with intellectual disabilities (who are also working there) and people without intellectual disabilities. Prisma puts into practice a care ethical stance by honoring vulnerability and capability, agency and precarious positions of all people. Although in recent years impressive results have been accomplished with the Red Carpet, participation and inclusion of persons with intellectual disabilities is still minimal. This is probably due to the fact that we do

not know what policy concepts as ‘participation’ and ‘inclusion’ exactly mean in the everyday lives of people with intellectual disabilities.
If we do not know what participation and inclusion mean for these people, then how can they successfully integrate in society? We used shadowing techniques to discover the everyday experiences of people with intellectual disabilities, since shadowing is a relevant technique for vulnerable persons who have difficulty articulating their experiences. During our contribution to this conference, we will give people with intellectual disabilities a voice by showing what happens in the everyday lives of these people in Kaatsheuvel and what this means for their participation and inclusion in society.

O – 24

Disability Management as effort to shape citizenship

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Aim

Older adults with life-long disabilities face challenges in their societal functioning due to health problems and their impact on daily life.
We wanted to identify strategies used by older adults with life-long physical disabilities to deal with the impact of their disability on their daily lifes.

Methods

In two focus groups, adults with life-long disabilities aged 50 years or older (n=10) gave voice to their experiences with aging and societal functioning. Thematic analyses were applied.

Results

Respondents indicated that their sense of belonging in society declined with getting older. To stay involved in society they applied a number of strategies, but they also faced barriers related to discrepancies between support needs and support services. These strategies varied from Taking initiative, Energy management, Medical management to preserve self-agency and Seeking support from peers. The strategies revealed a proactive attitude, and relate to Disability Management as a conceptual framework of different management roles required to build and maintain citizenship as a person with life-long disabilities.

Conclusions

Adopting the Disability Management perspective, citizens with disabilities are seen as actors instead of patients or frail human beings. For older persons with life-long disabilities, maintaining their place in society requires hard work. Although they need to balance between lower energy levels and the level of participation, they feel valuable for society and want to contribute. However, policymakers and healthcare/support providers hail a more vulnerable and paternalistic view, shaped by the concept of Frailty or Frail persons. Frailty, however, is hardly compatible with the emphasis on self-reliance (eigen kracht), nor with the work it takes to stay involved in society. Contrasting Frailty and Disability Management as two concepts to shape citizenship and the required support, we challenge Frailty as concept for living and aging with disabilities because of its normative and policy driven framework.

O – 25

Social Inclusion: working on belonging

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Aim

This paper explores the notion of social Inclusion, and puts this in the context of the work of professionals supporting persons with a disability. For persons with a disability, social exclusion can be caused by both physical and psychological segregation, related to the disability and/or because of a history of exclusion due to institutionalisation. Traditionally, in care services for persons with a disability, the focus was on individual care in relation to the disability. There was hardly any attention paid to participation in the community.

Methods

Under influence of notions of citizenship and the UN Convention on the Rights of Persons with a Disability, the focus is gradually shifting. For professionals working in the domain of care and support, it is a challenge to contribute to social inclusion. In this presentation, insights will be shared from a research project called ‘Expedition Inclusion’. At six places in the Netherlands, experimental practices were developed around the notion of social inclusion for persons with an intellectual disability.

Results

One of the findings is that working on social inclusion requires an ‘inclusive’ mind-set. This mind-set is based on values of equality and human rights. A second important finding is that inclusion is not something ‘big’ and unattainable, but that it can be concretised through different kinds of actions and activities. A third finding is that these activities take place in partnership and contribute to empowerment and mutual gain. The challenge is to create win-win situations, and thereby it is important for social workers to use the notion of reciprocity, while working on social inclusion.

Conclusions

1. Working on social inclusion requires an ‘inclusive’ mind-set. This mind-set is based on values of equality and human rights.
2. Inclusion is not something ‘big’ and unattainable, but that it can be concretised through different kinds of actions and activities.
3. These activities take place in partnership and contribute to empowerment and mutual gain. The challenge is to create win-win situations, and thereby it is important for social workers to use the notion of reciprocity, while working on social inclusion.
4. Inclusion oriented practices dismantle traditional institutional culture.

O – 26

Achieving social inclusion through personalised living and support

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Aim

In recent years increased emphasis has been placed on creating personalised living options for people with intellectual disabilities in contrast to the congregated arrangements of past decades. Supports for independent living embody the aspirations of the Convention on the Rights of Persons with Disabilities for greater choice and community participation. To date though, there is sparse evidence internationally as to the outcomes for tenants in personalised living arrangements, particularly with respect to their social inclusion.

Methods

This qualitative study examined the experiences of 34 persons in Ireland who had moved from congregated residential provision to more personalised accommodation and support arrangements.
Individual interviews lasting on average 45 minutes were conducted with the main support worker (n=31), the tenants (n=21) and, when available, relatives who had regular contact with the tenant (n=13). Interviews were conducted in the tenant’s home and, on average, two years after persons had moved to their new settings which typically took the form of rented accommodation in town settings with visiting staff for a number of hours per day. Interviews were audio-recorded and were transcribed word by word. Two authors initially undertook thematic analyses separately on a selection of transcripts. Discussion of emerging themes and sub-themes with the other two authors allowed for development of shared meaning. Themes were triangulated across the three informant groups.

Results & Conclusions

Personalised living had resulted in greater community participation and a widening of tenants’ social networks. The support workers played a significant role in helping tenants to reconnect with their family and with people in the community whom they had known previously. Joining existing community groups helped new friendships to develop. However

there was sparse mention of romantic relationships developing or of people gaining paid work. Concerns were expressed – mainly by relatives – of people being isolated in their home and the sustainability of the personalised arrangement if people required extra support.
Personalised living arrangements were effective in facilitating greater social inclusion of tenants but this required significant transformation in the role of support workers, the building of trusted relationships and increasing the self-confidence of tenants.

O – 27

The art of belonging: How do you know if you take part in society, as a full member of society?

Bianca Prins
Advisor Inclusive/Accessible Organizations, Krimpen aan den Ijssel, the Netherlands

Aim & Methods
How can we change the position of people with disabilities in society? Why do people with disabilities have to fight for their position in society on a daily basis? How does that impact your feeling of belonging?
My answer isn't short, it's very short: 'put aside' And as sad as it sounds, unintendedly it happens on a day to day basis. Even companies do this, by offering advertising without subtitles for example. This excludes deaf people in advertisements. Or by offering documents in small letters when a customer is unable to read these, due to poor eyesight. These small examples show that, by just doing our job, the way we use to do.
We're at risk of 'putting people aside' without realizing this.
Now the art of belonging comes in, how can we make sure that our disabled customers feel they belong to us? How can we take care of them in the best way possible?
This is quite simple, ask costumers for their needs, just start the conversation and there starts belonging. Being part of society, being part of the stakeholder community as customer or as colleague. Belonging starts with a conversation about how we can
support each other.
What will happen if we see disabled people as stakeholders? When companies, corporates and society tend to see people with disabilities as stakeholders. We offer independence, we offer a full place within our products, services and organizations. This is the start to an inclusive society!
The proven results in this type of businesses:

- Serves 80% of all customers
- Develop a new customer base
- Saves money by early developments instead of repairs
- Reduces service costs
- Builds a positive reputation

Accessible business is proven to be successful, let's make the corporate world inclusive and accessible!

O – 28

Level of social connectedness in neighborhoods as opportunities for social inclusion

Annica Brummel
Tandem Welfare Organization, Nijmegen, the Netherlands

Aim
This study into social inclusion on the neighborhood level focuses on social networks and communities from the perspective of the residents of the neighborhood with intellectual and developmental disabilities (IDD) or mental health problems (MHP). In this study, the capability approach (Nussbaum, 2001; 2011) is used. The value of the capability perspective lies in the aspect of human diversity. Social inclusion is not about adapting to the social norm, but about adaptation of the social norm. More insight is needed in the patterns which determine real opportunities for social inclusion.

Methods
Three very different neighborhoods in the city of Nijmegen are compared in a case study. We focused on neighborhood specific features which determine the process of social inclusion. 34 in-depth interviews were conducted with people with IDD or MHP. 27 respondents participated in group interviews as members of residents' groups, and 17 respondents joined four different focus groups.
The level of social connectedness focuses on how social interactions come about. In the three neighborhoods studied, different patterns of social inclusion were found, which were determined by a mix of various neighborhood characteristics, such as the number and type of public

facilities present and its image. In one of the neighborhoods, for example, social interactions mostly arose on the level of neighbour contact, but hardly in the social roles of volunteer.

Results

The accessibility of the residents' groups was determined by preconceptions towards people with a disability. Some residents' groups considered people with a disability as fellow residents, others considered them typically as patients. These preconceptions were also found on the individual level. The implicit identification with the role of client resulted in a double deprivation: it impeded participation in the community and it caused unequal personal social networks.

Conclusions

Most social interactions in the neighborhood arise from neighbor contacts. Other social roles, such as the role of volunteer, stimulate social networks as well as capacities. Therefore, volunteering often gives meaning to a regular daily program similar to a paid job. In this presentation we focus on the meaning and the real opportunities of social inclusion in the neighborhood from a capability perspective.

O – 29

Improving social participation of adolescents with visual impairments: a mentoring intervention

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Aim

Social participation is challenging for young people with visual impairments (VI). Since recent research has shown that a strong mentoring relationship has the potential for promoting youth development, a mentoring intervention, called Mentor Support, was developed to support adolescents with VI. Mentor Support consist of monthly meetings with a mentor and the content of these meetings is based on three domains; leisure, education/work, and social relationships. To test the effect of Mentor Support participants were randomly assigned to either one of the two experimental groups (mentors with and without visual impairments) or the control group. On three time points, at baseline, after 12 months, and after 18 months, interviews were conducted. Also cross-sectional data was gathered about the process of unrolling Mentor Support. These data gives us the opportunity to not only answer the question; is Mentor Support effective? but also; what are the pitfalls and opportunities with implementing a mentoring intervention for adolescents with visual impairments? Hence, we will present the outline of the program, outcomes of the course and the strength of the mentor-mentee relationships, and the results from program evaluations.

Methods

Translated questionnaires from the international Centre for Evidence-based Mentoring and Mentoring Central were administered by mentors and mentees to measure e.g. the strength of the mentor-mentee relationship. Also monthly evaluation forms were filled in by dyads after every meeting and an evaluation-interview was conducted after follow-up. To support mentors and mentees in developing a strong relationship, supportive telephone calls were made very regularly. These detailed transcribed conversations were coded and analyzed for recurring themes.

Results

In total 51 dyads took part in Mentor Support. Preliminary evaluation results show high ratings for Mentor Support; with a mean of 7.4 from mentors and 8.0 from mentees (within a range of 1-10). 80% of the dyads expressed to be highly satisfied with the quality of the dyads relationship. More extensive and in-depth results are forthcoming.

Conclusion

Dyads seem to be positive about the content of the program and their mentor-mentee relationship. These results might be beneficial for the effect of Mentor Support on improving social participation of adolescents with visual impairments.

O – 30

The role of belonging in quality of life of deaf adults in a home counselling program.

Corrie Tijsseling
GGMD (Mental Healthcare and social services) for deaf and hearing impaired persons, Gouda, the Netherlands

Aim

GGMD offers home counselling to early-deaf adults who have additional problems. Early deaf people are those who were born deaf or became deaf before the age of 3 years old. As 90-95% of deaf people come from hearing families, where spoken language is the primary means of communication, early deaf people have a significant risk of a language delay as their primary means of communication is visually oriented. The clients of the home counselling program of GGMD are diagnosed with a linguistic and/or cognitive problems, and/or psychosocial and/or psychiatric problems. A study of Langendoen and Huisman (2013) identifies these clients as outsiders, both in their own families as in the Deaf community.
Professionals who work with these people, tend to estimate their quality of life at a low level. However, Prins (2016) shows the discrepancy in outcomes between hypothetical and actual valuations of quality of life regarding a disability or illness. Deaf people usually value their quality of life as good, depending on the quality of their network, and their acculturation to the deaf community (Fellinger, 2005; Gerich & Fellinger, 2012). So far it has not been asked to clients of GGMD how they value their quality of life.

Methods

We constructed an online questionnaire, using the WHOQOL-BREF to measure quality of life and the Deaf Acculturation Scale (DAS) to measure acculturation into the Deaf culture and/or hearing culture. The questionnaire was offered in written language, Sign Supported Dutch (NmG) and Dutch Sign Language (NGT). 51 clients participated, with an evenly distribution of age, gender and educational level. Next to this, we used a “network circle”, to identify the width and quality of the social network of clients.

Results

Regarding quality of life we found that clients are very satisfied with their quality of life, which contradicts to the opinion of professionals. Regarding acculturation, we found a positive relation between acculturation and quality of life, indicating the importance of ‘belonging’. We also found a positive relation between the quality of a client’s network, and their valuation of the quality of their life.

O – 31

The importance of the method of ‘going into dialogue’ as an contribution to inclusivity, participation and to ratify positive self-image of people with a (mild) mental handicap, explained through two projects in Zeist.

Maria Nooren[1], Inica Loe[2]
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[2] Visual artist ‘Inica Productions’

Aim & Methods

The method ‘Go into Dialogue ’ offers a context of meeting, which is safe for people who join the circle call. Safe for people who are coming from different cultural backgrounds, ethnicities, positions and situations. When they exchange their own experiences around a common theme. The conversation is framed by a set of special ‘dialogue rules’. The most important rules are ‘no judgment, opinion or advice’ in the conversation. You speak from your own experience, there are no interruptions allowed and you listen carefully when someone else is talking. (During the presentation We will give some more explanation about this method, its creation as a result of 9/11 and the dialogue rules). This method has flared over The Netherlands and has in the last decade been applied in more than 60 Dutch cities by voluntary local groups. Inspired by ‘Netherlands in Dialogue’ who train and support the local groups developing their dialogue practice in order to diminish the ‘we and they’ thinking and to increase the awareness of our fellow human beings. Maria Nooren and Inica Loe present two projects of ‘going into Dialogue’ in Zeist targeting people with disabilities in 2017.

Dialooggroep Zeist vertelt over de waarde van de dialoog. Mensen met en zonder een verstandelijke beperking leiden de workshop.

O – 32

Why are middle-aged people with intellectual disabilities still lonely in their communities in Korea?

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Aim & Methods
This study aims to explore how people with intellectual disabilities in Korea experience loneliness even though they have lived in the communities for a long time. Data were collected through the 28 face-to-face interviews across the various local areas in Korea. Theinterviewees' age was ranged from 40 to 50 years old.

Results & Conclusions
As the participants get old, they have the changing family relationship due to their parents' death or aging. The participants' roles are changed from the care receiver to the care giver in both economic and emotional respects. They live with their families but have fewer daily contacts with their family members. They also have less relationship with their siblings than they had when they were young. One of their big problems is that they have no emotional support or counselling service after their parents' death, not unusually being moved to other places without being prepared. The second problem is that they have a very narrow range of social relationship. Usually, they have small and weak networks only with a few social workers at the community welfare centers, or personal assistants, or group home workers, or social workers at their workshops, or their peers at group home or workshops. Third, it was shown that, as they get old, they suffer from more emotional depression and worry about the fear of death, or lack of money, or no friends around them. The fourth problem is that the participants have moved several times from workshop to workshop until now. It means that they have undergone the frequent changes of peers, work environment, and salary level. These problems altogether contribute to make alone Korean middle-aged people with intellectual disabilities living in their communities, with no feeling of belonging to the communities. Recommendations are made to solve these problems or bring about some improvements as to them for Korean middle-aged people with intellectual disabilities to be more included in the communities.

O – 33

Participatory and responsive research into an 'Curriculum Experiential Expertise' for people with an intellectual disability

Gustaaf Bos, Rafaella van den Bosch, Miles Heinze
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Aim
First of all, we wanted to find out what it meant for both care recipients and care givers to be part of the curriculum 'Experiential expertise of people with ID'. Secondly, we wanted to gain insight in the perspectives of the commissioning parties, and evaluate to what extend the deployment of experiential experts had satisfied their needs.

Methods
The research team consisted of a university researcher and two self-trained co-researchers with an intellectual disability. We performed participant observations during the selection process, the training sessions and various deployment moments of the experiential experts. Besides, we conducted 13 semi-structured (duo-)interviews with 4 experiential experts, 4 coaches, 1 initiator, 2 commissioners, 2 project leaders, and 3 directors. Furthermore, we analysed the quantified deployment data of the curriculum. We also organized a focus group for both the experiential experts and their coaches. The data were thematically analysed by the research team.

Results
Many people mentioned a striking 'personal growth' of the experiential experts. Their growth was primarily shown by their ability to perform a (vocal, bodily or musical) presentation about their experiences, expertise and goals. Besides, many experiential experts partook convincingly in dialogue sessions and (research) projects with peers, care professionals

and social welfare students. The people involved often referred to the way in which the curriculum fostered ‘equality’ (coaches) or made the experiential experts feel at home or among friends (experiential experts).

Conclusions
Most of the 23 assignments consisted in the educating of groups of professionals and/or peers, both in- and outside the care organization. The commissioning parties reported a high satisfaction with the deployment of the experiential experts and were willing to pay for their eventual future activities. We think this curriculum also demonstrates that training experiential experts is not only about working towards ‘equality’, but also about a longing to interact with other people in a non-formalized way. One human to another. Apart from being addressed as ‘professional’ and ‘client’. Thus, it would be worthwhile to investigate to what extend the reported personal growth of the experiential experts is linked to the cumulating interpersonal relationships in the curriculum.

NL

Personen met een verstandelijke beperking hebben dezelfde rechten als iedereen. Dit vraagt om een samenleving waarin ze welkom zijn. Daarnaast moeten ze ook kansen krijgen om te leren. Speciaal onderwijs en dagbesteding in aparte settings levert hen niet altijd die leer- en ontwikkelkansen. Familie, coaches, begeleiding en betrokkenen moeten ook hun attitude veranderen en hun ondersteuning verbeteren. Mensen met en zonder beperking verzorgen deze workshop en stellen hier nieuwe methodes voor.

O – 34

Empowerment through personal development and cooperation

Gerard Nass, Henk van Dijk, Rietje Oomen
LFB Wolvega, Wolvega, the Netherlands

Aim & Methods
Mentally challenged people are citizens with the same rights as everyone. This demands a society in which they are welcome. Besides that, opportunities for learning are crucial. Mentally challenged people are disadvantaged by years of special upbringing, special education and separate labor arrangements. Development helps them for self-awareness, self-knowledge, self-management and self-advocacy. Also a different attitude is needed from family, coaches, supervisors and others involved, to work together for better support and social participation.
We contribute to this, together with peer workers, by making two methodologies accessible: “Stephen R. Covey’s” the Seven Habits of Highly Effective People’’ is translated into easy and understandable Dutch language. This to help people for more control and self-regulation by self-understanding, (better) understanding and making better choices. The starting point for personal development and collaboration are 7 timeless principles for lasting success.
Likewise, Roel Kok’s “door en voor” thinking, which emerged from the Dutch LFB Onderling Sterk, an organisation run by and for people with learning difficulties, is translated into easy and understandable language. This model is inspired by People First in the United Kingdom. Important are equality, opportunities to make mistakes, becoming more independent and taking responsibility. It is also the base for cooperation with peer workers and self-advocacy groups. Coaches support the use of the model in a way that they learn by themselves (think win-win).
Both projects are done in cooperation with 10 self-advocacy workers.
In our interactive demonstration we present and discuss the results of our work.

O – 35

New technologies and belonging: enhancement and dilemmas

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Aim & Methods
New technologies can greatly enhance the quality of participation of disabled persons, however, it is also evident that all kinds of problems emerge, such as questions of privacy, equity and moral issues.
New technologies englobe all the new possibilities offered by the ongoing integration between artificial intelligence, information and communication technologies, nanotechnologies and biotechnologies. For example, quite efficient assistant robots and care robots are currently developed which facilitate living conditions and communication opportunities of disabled persons. Another emerging technology has the goal to enhance the autonomy of disabled persons: Brain-Computer Interfaces (BCIs). BCIs

measure brain activity and translate that activity into commands for computers, wheelchairs or speech devices. BCI technology could help persons with locked-in syndrome (LIS), who are completely paralyzed but have intact cognition, to participate in social life.

These are just a few examples pointing to the opportunities offered by new technologies, which can indeed enhance the quality of participation. In this symposium, the organizers would like to use the cases of robotics and BCIs to illustrate how the development of new technology should go hand in hand with an investigation of ethical, legal and societal issues and open a general discussion how disabled persons can participate in the design processes of such technologies.

The quality of participation is one of the most important aspects of belonging, it points to the feeling of being part of social interactions, and of not feeling excluded.

However, these new technologies raise also new problems, such as questions of replacing interpersonal contact and of privacy. Moreover, the use of the new technologies confronts not only disabled persons, but also professionals and co- citizens with a number of dilemmas, such as ethical dilemmas.

To begin with, the use of these new technologies, for example robots in all their diverse forms is not only changing the identity of the users, it will also be linked to economic questions (for example saving costs), and it is feared that interpersonal contacts will be reduced, which could have dramatic

consequences.

A second point concerns privacy. As many of new products of the new technologies are connected to internet (and the internet of things), it becomes possible to collect data on the users continuously. In other words, privacy of users is extremely threatened. And that is a very important point, because the possibility of privacy is a necessary condition for persons to re-engage in participation.

Thirdly, new dilemmas emerge with the new technologies. We limit ourselves here just one example: persons with LIS (locked-in- syndrome) should as any patient give full consent to an intervention using the new facilities of brain- computer interaction, however that can be rather complicated or almost impossible. A serious legal and ethical dilemma.

Stream: Disability, History & Rights

O – 36

An eye-opening close-up of the working life of physically disabled labourers in Belgium, 1900-1920

Marisa De Picker, Pieter Verstraete
KU Leuven, Centre for the History of Education, Leuven, Belgium

Aim & Methods

In this presentation the history of physical disability is explored from an employment and re- educational perspective. During the first half of the twentieth century caring for physically disabled labourers became a responsibility of the State and society in Belgium. These individuals had a congenital disability or became injured by accident or war. Institutions were created to teach them a new profession, suiting to their remaining possibilities of movement.

Through re-education as many disabled persons as possible had to be transformed into economically valuable members for society again. However, not everyone could be helped by vocational training. With the expansion of re-educational possibilities, the need for alternatives became an object of thought too. Recently, scientific work on the history of rehabilitation and re-education has been growing, especially concerning male war veterans, but for Belgium few studies exist. Unlike many other studies in the field, this presentation about the Belgian case does not concentrate on the role of the State or medical experts in the organisation of re-education. Instead, it takes a close look at the specific working situations of labourers from different walks of life and with various disabilities. By detailed examination of their working life, new insights into their employment aspirations and perspectives are elaborated. In addition, it is analysed how disabled persons appropriated the practices and techniques that were taught to them. Participation in re-education and employment were a

complex commitment for disabled persons, made together with their teachers, medical staff and family. By trail-and- error labourers sought a feasible and interesting new profession, endurable assistive devices, work-life balance and a new identity. Four Belgian re-educational schools are discussed, based on state documents, medical reports and journals

of disability and labour organisations. Writings including the direct voice of apprentices are scarce.
Nevertheless, the research results provide a unique close-up of the vocational training period of Belgian physically disabled labourers between 1900 and 1920. Herein disability is visualised through a historical lens, but the focus is timeless: the hope shared by all disabled persons to find their own of way of living and belonging to society.

O – 37

Disability and Masculinity in Victorian Britain

Daniel Blackie
History of Science and Ideas, University of Oulu, Finland

Aim

Physical impairment in Victorian Britain threatened men's masculine identities, both in their own eyes and the eyes of others. This presentation examines the nature and limits of that threat by looking at the lived experiences of 'disabled' British mineworkers in the nineteenth century.
Utilising insights from sociological studies of disability and gender, it shows that injured miners had many options available to them to counteract the potentially emasculating effects of impairment on their identities as men. By doing so, it aims to encourage historians to pay closer attention to the historical agency of disabled people in defending their gendered selves from the challenges posed by disability.

Methods

A wide array of historical sources are used to develop the discussion. These range from memoirs and newspaper reports to census returns and Poor Law records. These documents are examined or information about definitions and experiences of disability and the everyday lives of mineworkers, particularly within their families and local communities.

Results

This examination reveals that nineteenth-century Britons often defined 'disability' as a complete or partial incapacity for work. Although paid work was undoubtedly an important measure of manhood in Victorian Britain and disability might undermine a man's gendered place in his family and community, it rarely changed it completely. Disabled mineworkers did sometimes have difficulties fulfilling the role of main family breadwinner, but there were other ways in which men could 'perform' their masculinity within their families and communities. Even if they were unable to work, many disabled men became or remained fathers, lovers, or even fighters, for example.

Conclusions

Such roles enabled injured mineworkers to significantly limit the potentially emasculating consequences of disability. Although frequently overlooked by historians, then, disabled people's lives as parents, spouses and sexual beings also need to be brought under the historical spotlight in order to better understand the complex interplay between disability and gender in the past.
Keywords: gender, disability history, identity.

O – 38

Writing to belong. Disability memoirs from across the Iron Curtain

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Aim & Methods

In this presentation I will explore two memoires that I have encountered while doing research for my PhD thesis on the impact of the UN International Year of Disabled Persons (1981) in Belgium, Poland and Canada. Both memoires are written by men of similar social standing but bring to the table life experiences that are informed by the differing historical living conditions for people with disabilities on contrasting sides of the Iron Curtain.
The manuscript for Prof. Jan Koteja's 1981 Rok niepelnosprawnych (1981 Year of the Disabled) was found and posthumously published in Krakow by his daughter, nun and poet Agnieszka Koteja. She added her own poetry, reflecting on her relationship with her father and his disability, to Jan's initial account in which he looks at his life as a wheelchair user through the lens of the cataclysmic year 1981. During this year the UN International Year of Disabled Persons was held, the communist government declared martial law in Poland and the labour union Solidarnosc was garnering nationwide momentum. In his 1978 memoires Handicap: onverklaarbare bondgenoot (Disability: an unexplained ally) Belgian journalist, writer and teacher Jean-Pierre Goetghebuer sets out

the ways in which he creatively rearranged his life to benefit his spinal cord injury . The former prospective priest who partially set aside his calling when he was immersed in the critical post-1968 atmosphere of an undisclosed student town reserves many a page for a biting critique of his alienating experiences with charities, rehabilitation facilities and the confusing tangle of administrative welfare regulations he is confronted with.

I will shed light upon and put in historical context the frequent instances in which the memoires of Koteja and Goetghebuer contemplate definitions of disability and how disability plays out in relation to other people – able-bodied and disabled persons alike. In particular I will bring to the fore examples of how both authors practice the art of belonging or artfully deal with occurrences of non-belonging, and illustrate how their sense of belonging as citizens is impacted by the different state regimes they were living in.

O – 39

Challenging Behaviour? Autism, Sexuality, and the Mythical Norm

David Jackson-Perry
Queen’s University, Belfast, Northern Ireland

Aim & Methods

Autistic voices have rarely belonged in research about autism, and this is certainly the case concerning the intersection of autism and sexuality. This absence conceivably contributes to the often unhelpful relationship between academia and some autistic individuals and communities. It may also be a factor in the abundance of literature concerned with autism and ‘challenging’, or ‘offensive’ sexual behaviour. Further, research identifies a significant proportion of autistic individuals whose sexual and gender identities and behaviour do not appear to conform to sexual norms when compared to non-autistic samples. How do researchers hypothesise this disparity, and what do these hypotheses tell us, perhaps less about autism than about prevailing perceptions of (hetero)sexuality and binary gender? What may emerge if the assumption of deficit and disorder is suspended when discussing the intersection of autism, sexuality, and gender? Here I explore the interaction of autism with sexuality and gender, distancing discussion from the dominant discourse of pathology and fear that so often pervades this area of research. I draw on existing literature in the domain and an online discussion forum to explore autistic experiences of sexuality and gender.

Results

Autistic accounts may do more than provide insight into autistic sexual and gender happenings. They also illustrate how, far from widening knowledge in the area, some research serves to perpetuate existing beliefs, prejudices, and perhaps arbitrary dichotomies: value-laden assumptions that autistic experiences may be uniquely placed to challenge.

O – 40

Cripping sex education: lessons to be learned from a programme aimed at young people with mobility impairments

Julia Bahner
Centre for Disability Studies, School of Sociology and Social Policy, University of Leeds, United Kingdom

Aim

The years spent in secondary school are influential among young people. It is an important time for developing one’s identity, social relations and sexuality. For youth with mobility impairment several aspects may influence this development. It can concern physical inaccessibility, judgemental attitudes, and inadequate sex education.

In Sweden, there are specific education programmes based on impairment types. Programmes aimed at young people with mobility impairment have designated habilitation centres and dormitories. Furthermore, the usual 3 years of secondary school can be prolong to 4 years.

This study aimed to investigate sex education in Swedish programmes aimed at young people with mobility impairment. This was previously unexplored.

Methods

This qualitative study included both pupils and personnel. Semi-structured individual interviews were conducted with 3 pupils. A focus group discussion was conducted with 3 other pupils. Two subject teachers were interviewed together. One sex education teacher was interviewed individually. A habilitation counsellor who ran discussion groups about sexuality was also interviewed.

Results
As for youth in general, issues concerning gender roles, sexual orientation, what is considered normal, and bodily ideals are central. However, being disabled raises additional issues that pupils want to discuss in sex education. This can concern ways to have sex or to conceive depending on bodily variations. Being reliant on assistants or family members may impact possibilities for privacy. Judgemental attitudes about disabled young people being asexual are experienced as tough on one's self-esteem. But not everything can be taught in school. Instead, pupils learn from each other and from searching the internet.

Conclusions
The interviewed pupils were largely content with their sex education. The issues they struggled with were instead related to societal barriers such as physical inaccessibility and asexualising attitudes. Therefore, attending a special programme was ambivalent. They may get their individual needs better met than in mainstream ones. But being there also makes it less natural to socialise with non-disabled pupils. That can impact their possibilities to fully participate in society.
Sex education needs to be 'cripped' so that pupils will have the tools to both develop their desired sexuality and challenge disabling attitudes.

O – 41

Powerfull connections with impact by diversity and mass

Aartjan ter Haar, Joris Barendrecht
Ieder(in), Utrecht, the Netherlands

Aim & Methods
The last months Ieder(in) did research for a combined online and offline tool which helps organisations for people with disabilities of chronical diseases. This tool we want to develop will be all the way with the support (hands and brains) of the people of the organisations.
Ieder(in) is a network of 250 organisations and want a better connection between them and with them. This way, we create a powerfull movement by diversity and the mass of this people. In line with the Convention on the Rights of Persons with Disabilities we create and devolop this tool. The research was stage 1 of this project. The people are enthusiastic and committed. This project will create chances to influence policy on local, regional and national level. We are very excited to start the next stages, 2 and 3 combined, to actually create the tool. This must be an online and offline project to get everyone committed to join in his or her way. Accessibility is an important criteria for both aspects.
This project also will change the way IedeR(in) works. We go upside down, where we were a top- down umbrella organisation, we will become a bottom-up network. People will support each other with knowledge and skills.
My colleague and I will present our findings and tell about why we made the choices we made and make in de process. We also will involve participants in the actual building of the network. Who are they, why are the here and would they join the network? And if so how? What is a trigger for them?

O – 42

Of History and Membership: Tanzanian Disability Activists, Global Citizenship and History

Sam De Schutter
Leiden University, Leiden, The Netherlands

Aim & Methods
In 1963, the Roman Catholic White Fathers established a 'Deaf-Mute Institute' in Tabora, Tanzania. When interviewing the director of the Tanzanian Association of the Deaf in 2017, he claimed that this was the "official start of the history of deaf people" in Tanzania. It might be tempting to read this statement as evidence of how the West exported knowledge about disability to Africa in the context of (neo)colonialism. On the part of the Tanzanian deaf organization, a kind of 'colonial nostalgia' might be brought up as explanation. In this presentation however, I will offer an alternative reading. I take this statement as a starting point to explore ways in which disability activists construct the history of a disability movement in Tanzania. Departing from the work by anthropologist James Ferguson, I contend that the way that these activists frame their own history is connected to issues of 'membership'. People with disabilities in Tanzania face at least a double exclusion. Because they have disabilities, they are marginalized in their own society, and because they are Tanzanian, they are excluded

from “full membership rights in a world society” (Ferguson 2002:559). These forms of exclusion become intrinsically linked in how Tanzanian disability activists construct their ‘collective memory’. I will analyze their historical recollections and examine how they use their history in claiming both national and global membership. Apart from exploring issues of ‘belonging’ in a Tanzanian context, I also use this analysis as a starting point to break through the current ethnocentrism of disability history. Through the use of oral history interviews, I will offer one way of historically examining disability in an African context, firmly embedded within global developments.

O – 43

Listening to emancipation: Sound and the liberation of persons with a visual disability in Belgium, 1900-1940

Pieter Verstraete
KULeuven, Centre for the History of Education, Leuven, Belgium

Aim
In this presentation I will use an acoustic approach in order to study the emancipatory processes of persons with visual disability in Belgium during the first half of the Twentieth Century. This means that particular attention will be paid to the different roles played by sound in the attempts of Belgian persons with visual disabilities to liberate themselves from discriminatory societal prejudices. The research is based on a wide range of historical source material, but focusses in particular on the different Belgian so-called blind journals that were published in the Interwar years, namely: Sint-Lutgardisblad, Alexander Rodenbach, Algemeen Blindenverbond van Vlaanderen & Vers La Lumière.

Methods
On the basis of an analysis of the historical source material it will be demonstrated 1/that an acoustic approach of the history of emancipation is possible 2/that sounds have triggered particular emancipatory processes but also have been used in order to realize emancipatory goals 3/that at least for the Belgian context a shift seems to have taken place in how emancipation was conceived: if around 1900 the emancipation of persons with visual impairments among others things can be interpreted as a particular answer to the sound of the other, after the Great War emancipation became much more focused on safeguarding the sound of the self. This central argument will be developed by taking a closer look to a parliamentary petition of blind pupils against the blinding of finches (1901) and demonstrating that the white cane was introduced in the Interwar Period in response to the noise and dangers posed to the blind by modern traffic.

O – 44

The Art of Belonging: A Personal History of the Disability Movement at the European level

Johan Wesemann

Aim
This paper investigates the meaning and impact of the self-organisation of people with disabilities at the European level and more in particular the history of the European Disability Forum (EDF) as part of the Helios programme of the European Commission. The viability of the EDF was contested since its foundation in 1993, but this cross-disability organization has proven to be successful in stimulating equality for all.

Method
Based on personal experiences, historical source material and secondary literature a reconstruction will be made of the factors that made it possible that self-advocate organizations of different disability groups and from various countries realized and worked together in one organization that represents the voice of people with disabilities at the European level. Moreover, the history of EDF will be analysed through the lens of New Social Movements Theory with special attention for the role of the human rights framework and concepts like emancipation and equal opportunities.

Results
This historical reconstruction makes clear that the self-organization of people with disabilities on the European level is part of the globalisation of the disability movement in the 1980s and 1990s, that was stimulated by the disability policies of the United Nations. Furthermore, the history of the EDF will be explained by developments of the European Commission and of national self-advocacy groups during these decades.

Conclusion

The self-organisation of people with disabilities at the European level was and is important for the emancipation of people with disabilities and for their art of belonging. However, this paper makes also clear that emancipation is a never ending story: different factors play a role and governments do not give equal opportunities ‘automatically’. Therefore the improvement of the education of and the public perception about people with disabilities is of utmost importance.

O – 45

Equality for All, Photo Essay

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Kristín Björnsdóttir
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Reykjavík, Iceland

Aim & Results

This presentation is based on a narrative photo essay which tells the story of our project Equality for all. In January 2016, we were hired by the University of Iceland to work on this research project which aims to explore the ideas of men labelled as having intellectual disabilities regarding equality with a special focus on gender equality. Since we started working on this project we have participated in various academic and non-academic activities and we will provide pictures from our participation in national and international academic conferences and our workplace. In the summer of 2016 we became guerilla artists, i.e. designed posters and artwork on the issue of equality and displayed (without permission) in public places in Reykjavík. In our presentation we will show pictures of our guerilla art and our participation in activism e.g. from a meeting with the newly elected president of Iceland Guðni Th. Jóhannesson, our participation in Reykjavík Pride 2016 where we distributed postcards with statements on equal rights and pictures from our participation in the grass root festival Disturbing Existence which was organized by the National Queer Organization of Iceland and Taboo, feminist organization for disabled women. In our presentation we will discuss the issue of access, e.g. access to information, conferences, and activism. We will introduce our Facebook page and describe how social media can be inaccessible to people labelled as having intellectual disabilities and also ineffective as a tool for activism. We have made attempts to use Facebook to present photo essays on different themes extracted from the Convention on the Rights of People with Disabilities: the right to employment, education, participation in culture, and on the theme of the rights of disabled women. We are committed to give our presentation in plain and accessible language. Our colleague and coconspirator, Kristín Björnsdóttir Associate Professor in Disability Studies at the University of Iceland, will be our assistant and provide audio description of all images in our presentation.

Gelijkheid voor iedereen, een verhaal met foto’s

IJslandse onderzoekers en activisten vertrekken vanuit het verdrag voor de rechten van mensen met een beperking en speciaal vanuit: recht op goed werk, onderwijs, cultuurparticipatie, en het recht op een goed leven voor mannen EN vrouwen met een beperking.
Ze noemen zichzelf guerilla artists: ze gaan in de samenleving het thema gelijkheid onderzoeken, en aanklagen, en vragen hiervoor geen toestemming.
Ze presenteren met foto-verhalen en ondertitelen de foto’s met heldere gesproken taal.

O – 46

The UN CRPD ratified; the first step to a barrier-free society?

Tanja Mol, Mitzi Waltz, Elinor Gittins
Disability Studies in Nederland, Amersfoort, the Netherlands

Aim

In July 2016 the Netherlands signed the United Nations Convention on the Rights of Persons with a Disability (UN CRPD). It states disability is part of human diversity, but recognizes that persons with a disability still face barriers. By signing this convention, the Netherlands requires national and local governments as well as individuals and businesses to recognize that all members of society deserve equal access. “In the end there will arise an inclusive society,” as one expert by experience stated.

Methods
Background began with a thorough literature review on (inter)national laws and regulations and the impact of the UN CRPD in other countries. A series (n = 26) of semi- structured interviews were held with experts by experience, policymakers and advisors, the first Dutch UN panel, disability experts and others. This data was then analyzed to discern key issues and concerns in an iterative process by open coding.

Results
“Raising awareness is the seed that lets the plants grow,” was mentioned by a UN ambassador: a volunteer in the Netherlands who shares knowledge about the UN CRPD to help others. Public awareness is expected to result in visible changes over time, mainly for people with physical or sensory disabilities. In the short term, most interviewees expect activities to take place that raise awareness of barriers that persons with a disability often face within Dutch society. This is in line with the implementation plan from the Dutch government, published in March 2017, which describes its strategy to create an inclusive society. The interviewees expressed a range of expectations, from high hopes for change to scepticism surrounding the implementation plan and putting policies into practice. Once analyzed, this research presented a reality check as to where we are as a well-developed nation that nevertheless presents many challenges to disabled people in their daily lives.

Conclusions
Signing the UN CRPD will help break down the physical, legal and social barriers that impact persons with a disability in the Netherlands. Changes are not expected immediately, but making disabled peoples’ rights legally binding is a start towards an inclusive society without any barriers for anyone.

NL

Het verdrag voor de rechten van mensen met een beperking; de eerste stap naar een samenleving zonder drempels?
Eten is belangrijk! Niet alleen lekker eten, maar ook gezond eten, en gezellig samenzijn, en toegang hebben tot plekken waar eten is… De sprekers vertellen in deze workshop over hun onderzoek ‘Aan tafel!’ naar voeding en toegankelijkheid, en wat dit betekent voor mensen met een beperking, hun rechten, en voor de samenleving.

O – 47

Disability, access to food and the UN CRPD: Navigating a rights-based equality discourse in the Netherlands

Mitzi Waltz, Elinor Gittins, Tanja Mol
Disability Studies in Nederland, Amersfoort, the Netherlands

Aims
In 2016, the Netherlands ratified the UN CRPD, becoming one of the last developed nations to sign on. In this presentation, we will explore how equal access to food provides a lens through which barriers to implementing a rights-based approach to disability equality can be examined in countries that are historically resistant to rights-based equality discourses.

Methods
Through a literature review, policy research, and interviews with disabled people, representatives of disabled people’s organisations, Dutch legal scholars and government representatives, food system researchers and food banks, we have explored barriers to equal food access in the Netherlands and multiple approaches to overcoming social, economic and physical barriers.

Results
Analysis indicates that implementation of the UN CRPD and other relevant international and EU policies continues to be limited in the Netherlands due to narrow interpretations, leading to policies and practices that do not foster equal access to resources and environments. Dutch understandings of disability equality are evolving, but encounter opposition from an entrenched system of separation and resistance to mandating change, including a reluctance to even collect data about inequality.

Conclusions
In our conclusion we will present information about gaps in the knowledge base, and we will also make recommendations for steps the Netherlands could take to create truly inclusive policies and practices.

O – 48

Life After Violence, how women with intellectual disabilities cope with institutionalised violence

Juultje Holla[1], Ellis Jongerius[1], José Smits[2]
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Aim
This is a study on how women with intellectual disabilities cope with institutional violence. Women with disabilities are more at risk of violence. Violence takes on many forms in an institution.
They have fewer chances to report it. And less support to move on afterwards. There has been a lot of research into the violence that takes place in some institutions. But not much at all on what happens to these women afterwards. Violence causes stress and pain. To remove someone from institution is not enough. People need help and support to cope in the community. Inclusion Europe is going to do a study in the Netherlands. We want to better understand the situation. That way we can learn what will help. And how to improve women's lives after institutional violence.

Method
We use qualitative research methods. We want to know what women have experienced. This is hard topic to talk about. We make stories that can not be connected to any single person. We will discuss these with parents and other people involved.

Results and Conclusions
We have talked to female self-advocates with intellectual disabilities about what they think of when talking about violence in institutions.
We will present these results and talk about the methodology. We are still working on collecting data to establish what the results and conclusions of our research will be.

NL

Vrouwen met een verstandelijke beperking ervaren verschillende soorten geweld, ook in instellingen. Juultje Holla, Ellis Jongerius en José Smits onderzoeken verschillende vormen van geweld, zoals deze ervaren worden door de vrouwen zelf. Ze onderzoeken ook wat voor invloed dit heeft op deze vrouwen, in het bijzonder wanneer ze in de samenleving gaan participeren. Aan de hand van tekeningen presenteren ze hun onderzoek tot nu toe. Ze doen ook actieve oefeningen. De onderzoekers zijn benieuwd naar ervaringen, vragen en ideeën van het publiek.

Stream: Inclusive & Creative Methods

O – 49

Reflection of a 3-year collaboration between researchers with and without intellectual disabilities

Tessa Frankena
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Aim
The aim of this study was to reflect on a three-year collaboration between researchers with and without intellectual disabilities regarding the different roles researchers with and without intellectual disabilities played within this collaboration.

Methods
Three groups of stakeholders were interviewed: (1) the inclusive research team (n = 3), (2) direct colleagues (n = 8), and (3) management staff (n = 2). Additionally, group discussions were held within the inclusive research team using a timeline developed during the three-year collaboration. The study itself had an inclusive character, meaning the study design, data collection, and data analysis were done collaboratively. Data analysis was done using Membership Categorisation Analysis.

Results
Where researchers without intellectual disabilities merely played the role of "researcher" and "supporter", researchers with intellectual disabilities played a broad spectrum of roles: (co-)researcher, expert-by-experience, advisor, advocate, teacher, and presenter. Researchers with intellectual disabilities grew into these roles and felt more comfortable in

taking on new challenges as they gained more experience. Management staff identified challenges with the researchers with intellectual disabilities in the role of “employee”, however, they experienced similar challenges with the employment of research staff in general due to current legislation.

Conclusions

Working collaboratively is contagious, however, researchers without intellectual disabilities need time to get used to the multitude of roles they play within research. Awareness on and identification of these roles could help support researchers with ID collaborate in research. Likewise, it would support researchers with intellectual disabilities in their role of supporter for researchers with intellectual disabilities.

Terugkijken op een samenwerking tussen onderzoekers met en zonder verstandelijke beperking

Waar het over gaat

Henk, Anneke en Tessa hebben 3 jaar samengewerkt in een onderzoeksproject. Ze deden onderzoek over hoe onderzoekers met en zonder een verstandelijke beperkingen (VB) samenwerken.

Ze hebben teruggekeken op hun samenwerking door 3 groepen te interviewen:
1. het onderzoeksteam;
2. de directe collega’s; en
3. de managers.

Ook hebben ze groepsgesprekken gehouden met zijn 3-en aan de hand van een tijdlijn.

Henk, Anneke en Tessa hebben geleerd dat onderzoekers zonder een VB maar 3 rollen hebben: wetenschappelijk onderzoeker, regelaar en opdrachtgever.
Onderzoekers met VB hebben wel 5 verschillende rollen: co-onderzoeker, ervaringsdeskundige, adviseur, vertaler en docent.
Zowel onderzoekers met en zonder VB als collega’s hadden tijd nodig om aan de samenwerking te wennen.
In de loop van de tijd werd de samenwerking “besmettelijk” en gingen steeds meer collega’s samenwerken met onderzoekers met VB.

O – 50

Inclusive research: How do we start?

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Portuguese Association of Parents and Friends of Citizens with Mental Disabilities (APPACDM) of Castelo Branco, Portugal,

Aim

Inclusive research is an emerging research paradigm that encompasses a number of forms of conducting research, all of which focus on researching with people with intellectual disabilities (ID) rather than about them. Including the perspectives of individuals with ID may provide an important contribution to research, since they are in a good position to provide insights into their own experiences, wants, and needs. The aim of this work is to describe the implementation process of an inclusive research project in a day care service provider in Portugal.

Methods

The participants of the project are five persons with ID and a clinical psychologist and Ph.D. student. The participants with ID attend the occupational center of a day care service provider. The main aim is to increase their autonomy, exercise of choice and cognitive abilities and promote their empowerment. The project will have two main phases, the first one will be an inclusive research programme and the second one the development of an inclusive research by the all the participants, involving other colleagues from the day care service provider as subjects. The first phase, the programme, will help to learn necessary research skills and explore the importance of research, why we should do that and how to do that in an accessible way. This programme will have 12 sessions. In the end of all sessions, the participants will do a report and a reflection that will be analyzed, to understand the impact of the programme.

Results & Conclusions

People with ID should have the opportunity to participate in inclusive research projects because their perspective can provide a fundamental and enriching contribution to research. In all the processes is important to apply different and active methods, and use accessible language. It is an important research decision to give voice to persons with ID and learn from their perspectives and opinions.

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Working together with people who are communication vulnerable in research.

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Aim

People who are communication vulnerable are often excluded from research, because of their communicative or cognitive disabilities. We define people who are communication vulnerable as people who -due to a medical condition- have difficulties in expressing themselves and/or understanding information. Little is known about how to involve them in a meaningful way. The objective is to explain promising tools and strategies to include people who are communication vulnerable in research.

Methods

We developed an experience-based instrument using a human centered design process (February 2016- July 2017). We worked together with people with a learning disability, neurodegenerative diseases or acquired brain injury and their caregivers. The project consisted of four phases: (1) literature study, (2) prototyping, (3) usability testing (think aloud and semi- structured interviews, observations) and (4) feasibility testing (interviews, observations). The data was analyzed using a usability testing framework. The experiences are presented together with experience experts.

Results

We will give insights in how researchers, patients and caregivers experienced the facilitating strategies in each phase of the research project. A participation matrix will be presented which indicates when, where and how people who are communication vulnerable participated. We will also explain how we adjusted the communication. Important themes are: structuring meetings, small agenda-setting, visualization and hospitality.

Conclusions

Including people who are communication vulnerable in research is challenging, however, strategies are available to give this vulnerable group a voice. Their perspective enriches the collaboration, improves usability, and contributes to experiential knowledge. This presentation gives insight in which strategies can be used to include the broad target group of people who are communication vulnerable in different research phases.

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Flirt Fantasies – What do you think when you look at me? Choreographing, performing, and appreciating inclusive arts as a ‘practice of knowing’.

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Aim

The process and work around Flirt Fantasies started in March 2015. Now we are a year ahead and the 30 minute work is almost finished. However, how did the traditional concept and idea developed into a product as it is now? The aim is to reflect on the practice. What happened in position and in relation to different bodies – dancers, audience and myself.

Methods

The work ‘Flirt Fantasies’ danced by 3 woman is about the identity of woman in modern society. For example how we deal with our online identity in dating apps. How do we place ourselves within this world and where do we start our search to and for love? ‘Flirt Fantasies’ is about communication and interaction or lack of that. Alienation of yourself and others. The first eye contact ... the first thought “What do you think When you look at me?” The voice over from Dalia Mogahed (TED talk) and the projection of the live streamed Gopro camera explains it all. It gives an extra dimension to topics like ownership, embodiment and identity.

although however, as an inclusive dance company and working with a dancer with Down Syndrome the interpersonal relationships became important. In situations in the studio, outside the studio and while we were performing. During the process, the bodily way of connecting to bodies was challenging a ‘special’ power structure. Those of the audience and those of the dancers. Relationships within the dance studio changed and shifted constantly between me and my dancers. The practice became an embodied knowledge and intuitive way of interacting and making work. A reflective process where we dealt with a degree of ownership within the inclusive arts. Because of sickness we had to work with another dancer with Down Syndrome. The embodied knowledge, interaction and the interpersonal relationships became more clear by reworking the piece and working with another dancer.

Working on the last section and having the opportunity to tour the work internationally I feel the work has no final expiration, but carries a lot knowledge within.

NL

Flirt Fantasieën

Het proces en werk rondom ‘*Flirt Fantasies’* begon in maart 2015. Nu zijn we een jaar verder en het 30 minuten durende werk is voltooid. Hoe heeft het traditionele concept en idee zich echter ontwikkeld tot een product zoals het nu is? Het doel is om na te denken over de praktijk. Wat gebeurde er in positie en in relatie tot verschillende lichamen – dansers, publiek en ikzelf.

Het werk *‘Flirt Fantasies*’ met 3 vrouwen gaat over de identiteit van de vrouw in de moderne samenleving. Bijvoorbeeld hoe we omgaan met onze online identiteit in dating-apps. Hoe plaatsen we onszelf in deze wereld en waar beginnen we onze zoektocht naar de liefde? *‘Flirt Fantasies*’ gaat over communicatie en interactie of gebrek daaraan. Vervreemding van jezelf en anderen. Het eerste oogcontact ... de eerste gedachte “Wat denk je als je naar me kijkt?” De stem van Dalia Mogahed (TED-talk) en de projectie van de live gestreamde Gopro-camera verklaart alles. Het geeft een extra dimensie aan onderwerpen als eigendom, belichaming en identiteit.

Echter, als een inclusief dansgezelschap en in samenwerking met een danser met Downsyndroom werden interpersoonlijke relaties belangrijk. Dit gebeurde in situaties in de studio, buiten de studio en terwijl we aan het optreden waren. Tijdens het proces daagde de lichamelijke manier van verbinden een ‹speciale› machtsstructuur uit. Deze was aanwezig bij het publiek en de dansers. Relaties tussen mij en mijn dansers veranderde en wisselden voortdurend in de dansstudio. De praktijk werd een belichaamde kennis en een intuïtieve manier om met elkaar om te gaan en werk te maken. Een reflectief proces waarbij we een deel van het ownership binnen de inclusieve kunsten behandelden.

Vanwege ziekte moesten we werken met een andere danser, ook met Downsyndroom. De belichaamde kennis, interactie en de interpersoonlijke relaties werden duidelijker door het stuk te bewerken en met een andere danser samen te werken. Werkende aan het laatste deel van het stuk en tijdens onze internationale tours ervaar ik dat het werk geen einddatum heeft en constant evolueert. Het draagt veel belichaamde cognitie van binnenuit.

O – 53

Making a more inclusive art world: belonging, relating and creating

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Aim & Methods

Inclusive art is often seen as a charitable practice or part of providing art therapy, rather than a professional occupation and practice. In this framework, art is important to people with disability only insofar as they can provide therapeutic values by giving them a setting for self-expression. This assumption traps people who engage with inclusive art practices, such as artists, performers and choreographers, into a therapy setting, where enactment of art ‘for art’s sake’ is not possible.

In governmental or community funding application processes, an inclusive art organisation is often categorised as a disability care organisation, rather than a professional art organisation. Also reflecting this assumption, there is a deep-rooted reluctance in the art sector towards exploring the creative potential of people with disability.
Of course, therapeutic properties of artistic endeavours have been well documented for both disabled and non-disabled individuals. However, disabled people have restricted freedom of movement between the ‘therapy’ and ‘art’ worlds, because the societal attitude and institutional arrangements, including a lack of financial and public recognition for inclusive arts, push their activities into the frame of therapy. This means that, in order to claim a space and belonging in the art world, inclusive art practitioners have to constantly engage in various strategies to ensure that their work is recognised as art. In this paper, we articulate this process by presenting a case study of Misiconi, an inclusive dance company based in Rotterdam. Drawing on data collected through participatory qualitative research methods including interviews and observations, we illustrate how these strategies can be understood as attempts to enact art through relationships of individual, social, and political actors, such as the performers, family members, choreographer, audience, funding bodies, and other art companies and artists. This process also involved various things, such as props, performance venues, website, and social and digital media. It was enabled or disabled at the organisational and individual levels, as inclusive art practitioners negotiated the notion that the bodily capacity equates to the ability to produce something tangible, measurable and consumable.

O – 54

In praise of visibility: how art can change our perspectives on disability

Doortje Kal, Gustaaf Bos, artists of studio “bij Johannes”
National Support Centre Kwartiermaken, VU Medical Center, Dept. of Medical Humanities, Amsterdam, the Netherlands

Aim & Methods
Our session will be ‘in praise of visibility’, in line with the work of philosopher Rudi Visker (2007). The oral presentation is both inspired and illustrated by the work of an art collective of painters with an intellectual disability, who created paintings about ‘encounter’, ‘participation’ and ‘belonging’. They all work for studio ‘Bij Johannes’ [Transl. ‘At John’s’]. Doortje Kal will present some thoughts inspired by Visker, who points at the importance of this ‘coming out in the open’.
He claims that showing oneself in word and deed to others, brings about a change in people. In that sense, the public space is a productive space. An exposition in the public space enables amateur or professional artists to be not alone in their otherness. Instead, sharing their work might facilitate mutually stimulating and enriching encounters between people from the mainstream and the margins of our society.
In line with this, Gustaaf Bos will talk about his ambition to create a ‘community of practice’ (Wenger, 1998) around artistic encounters between people with and without intellectual disabilities. Encounters which might alter our perspectives on ‘normality’ and ‘otherness’. Pieces of art, like those of Cor de Jong and his colleagues, offer them an opportunity to show the world outside another site of who he is. In that, not his disability is central, but his artistic talent. By showing their work in the public realm, Cor and his colleagues have an opportunity to shed new light on the often one-sided (and negative) public image of people with intellectual disabilities.
Thus, in this exposition, as well as in our oral presentation, we all want to express the longing of everyone whose being in the world is not self-evident – not ‘normal’ – to belong.
To participate and belong, each in their own way. We see expositions like this as a suitable means to work on more space for ‘being other’.
The public space is not just for ‘standard people’. On the contrary, the public space is open for everyone we are willing to relate to.

O – 55

Inclusion and Churches: an Ecclesiological Contribution

Koos Tamminga, H.Blom-Yoo
Theological University Kampen, Kampen, The Netherlands

Aim & Methods
Inclusion is an ideal on many levels. Ideally, the Dutch society is an inclusive society. The government uses the language of inclusion when they make laws. But this does not mean that those who work with those laws have an inclusive mindset. Many people in society do not have such a mindset. This is why some researchers have called for ‘ethical communities’. In those communities values are shaped so all can belong.

In this presentation I want to suggest that churches might be such communities. Churches have a difficult history when it comes to disability. They have provided care. But they have also unwillingly promoted discrimination. Today, governments try to partner up with churches. But this is also complicated. Is the church indeed a fit partner for governments who look for a more inclusive society? And what could non-governmental organizations expect from the church? In the presentation I want to share some issues that I have come across in my research. In my research I follow Hart van Vathorst (HVV). HVV is a place where about 100 people with various disabilities live and work and go to church, if they want. The church is also the church of the people who live around HVV. It is in the neighborhood of Vathorst in Amersfoort, the Netherlands. This project started in March 2016, so it is still just beginning. In HVV people are trying to live together in an inclusive way. This has many benefits. But is also difficult sometimes. HVV can only be a success if all church members get an inclusive mindset. Their values need to be shaped. The example of HVV shows us that it is important to look at the motivation. What is the story of inclusion or belonging? And how is this story communicated? Not just on the level of politics, but also to normal citizens. Is it realistic to think that everybody will change? Does society have enough motivation to reshape values? Maybe churches can be places where the story of inclusion is shared. But then it is also important to think about theology. What is the story of the church and how can it help society? This is the most important question of my presentation.

O – 56

RAMP: How a struggle over access inspired a beer

Jascha Blume, Nunzia Vanuccini

Aim & Methods

In 2015 we opened our cultural café L'Altro Spazio in Bologna. A dream come true, it soon became a hip, arty meeting place for people irrespective of disability, shape, size, colour or background. Access and inclusion are fundamental to L'Altro Spazio.

People with disabilities usually have to 'work' to belong. Here they work in a different way: as colleagues. Most of our team at L'Altro Spazio have a disability. We're contributing to an accessible society because we are open to visitors and colleagues with or without disabilities. Not that accessibility and communality come automatically: we have to work at making everyone feel equally welcome. The result is a beautiful, inclusive diversity in which art plays a central role and which is unique in Europe. All our menus are available in braille, whilst staff can communicate in sign language. The bar is designed to accommodate wheel chair users both in front and behind. We organize weekly events: music, performances in sign language, poetry slams, exhibitions, 'dinners in the dark' etc. In this way we let visitors without disabilities understand and experience how much 'work' needs to be done to be part of and included in an inclusive world.

Realising our dream for L'Altro Spazio, has involved an arduous process of negotiating with authorities, getting permissions, fighting prejudices. We have recorded this whole process with a camera and compiled a short documentary from it. Our struggles with the municipality of Bologna over the ramp for wheel chair visitors – which resulted in a number of fines – will be central. We are teaming up with the Bologna disability organisation to bring this municipal decision to court. But we are also replying in a way that fits the philosophy of L'Altro Spazio. We asked a well-known Deaf American brewer to come over to Bologna and brew a special beer for us. The beer we called Ramp and the label we designed shows an artistic impression of our wheel chair bar lady. L'Altro Spazio has received much attention in the Italian media.

L'Altro Spazio is an initiative of Nunzi Vanuccini en Jascha Blume. Nunzia is Italian, has a background in film studies, and established a disability film festival in Bologna. Jascha is Dutch, graduated in video art from the Rietveld Academy, regularly exhibits, and has been active in the Dutch Deaf movement.

O – 57

Caring relationships around acquired brain injury (ABI): mapping moral complexities

Susan Woelders, Annette Hendrikx, Suzanne Metselaar, Karen Schipper, Tineke Abma, Bert Molewijk
VU Medical Center, Department of Medical Humanities, Amsterdam, the Netherlands

Aim & Methods

ABI causes diverse and often hidden disabilities. It can develop quite sudden and requires enormous adjustments in roles, relationships and responsibilities within the family. Furthermore, both people with ABI and family members can become suddenly dependent on professionals and need to find a new balance in their caring responsibilities. For a long time, family has been structurally undervalued in (long-term) health care. Their care ethics, activities and needs were not constructively explored. Currently, a new wind is blowing (e.g. the participation society) and the role of family care is revalued. Due to this societal transition, more focus lies on self-reliance of people, and more care and support is expected from family, whereas formal professional care is reduced. Furthermore, professionals are to collaborate with family members in the distribution of care practices. This means that responsibilities about care and support have to be attuned between (1) people with ABI whoneed care and support, (2) their family and (3) professional caregivers. In practice this raises questions: who is responsible for what? How do all those involved attune care and support? What are their moral expectations? And what struggles do they experience? What happens when the two (moral) systems, professional care and family care, meet and/or conflict? These questions were the focus of our responsive, empirical research. We collected stories of people with acquired brain injury (ABI), their family member(s) and their professional caregivers and we mapped the moral complexities within these triads in order to shed light on the specific moral issues that these stakeholders have to deal with. The aim of our study was to develop an ethics support tool that can provide support to the stakeholders in dealing with the moral challenges related to their caring responsibilities around ABI. In this presentation we will go into the specific moral dilemmas identified in these triads, and into the ethics support instrument we are developing.

O – 58

Violent life in an inclusive classroom: Come on, READ, Andreas! Moving from moral judgment to a diffractive, ethical analysis

Inge Van de Putte
Ghent University, Inclusive Education and Disability Studies, Ghent, Belgium

Aim & Methods
The purpose of this narrative woven autoethnographic study is to examine the role of working together on (dis)abling access in a relational way through out an educational context. Inge and Elisabeth both worked as support workers of Anna, a girl with severe, communicative and physical difficulties while she was attending primary school (1999- 2005). Anna had a direct budget, so it allowed her (and her parents) to have control in the way support was provided. The supporters worked in daily life at home, in class and during leisure time to increase participation in society. Inge and Elisabeth draw on their experiences of disability and support in primary education and their allied identities to discuss and examine questions of access, belonging and inclusion. Belonging represents a critical analytic lens through which these support workers examine their positions, understandings, regimes of practices, and particular knowledges. Inge and Elisabeth discuss their experiences of disablement, working together and reflections on support and disability.

O – 59

Collaborative Research: Power and Possibilities

Hanna Peels, Britt (Beau)
Middin, the Hague, the Netherlands

Aim & Methods
The presenters have been doing research together on longterm care, disability & identity. Context: we have analysed blogs written by one of the presenters. The blogs are about living in an institution for people with disabilities. We have discussed the development of identity and position of a person with disabilities, using the insiders perspective of Beau, one of the presenters. What: on the presentation we would like to share our experiences in performing research together. We have grown together as researchers and humans. We have overcome a few pitfalls and have adjusted our cooperation. How: the presenters will discuss these pitfalls and adjustments by interviewing each other. Those attending will be invited to contribute to the discussion. Specific attention will be paid to the concept of ‘power analysis’ at the start of the research project.

De kracht en mogelijkheden van inclusief onderzoek
Oesters en parels, monnikenwerk en dé weg naar Rome… Een eerlijke samenwerking in onderzoek, hoe bereik je dat? Hanna Peels en Beau werken samen aan een onderzoek waarin de blogs van Beau geanalyseerd worden op levenslessen voor de zorg voor mensen

met beperkingen. In deze workshop bevragen zij elkaar over wat zij in hun participatief onderzoek geleerd hebben over samen onderzoek doen. Er is speciaal aandacht voor hoe Hanna en Beau een power analyse vervlechten in de samenwerking.

O – 60

Longing to belong: Proposal of the ‘Art & Care Group’ (Kunst & Zorg)

Merel Visse, Alistair Niemeijer, Alice Schippers,
Jacqueline Kool, Truus Teunissen, Sanne Rodenburg
Art & Care Group of the UvH and DS, Amersfoort,
the Netherlands

Aim & Methods
According to Marcel Kolder, who is a Dutch blogger and father, when you care for a disabled child, ‘carefree longing ceases to exist’ (‘Een ongedwongen verlangen bestaat niet meer’). In a time when ‘who cares for whom’ is a much debated socio political issue in modern western societies, the topic of longing and belonging is at the forefront. Often, these discussions focus on the political dimensions of belonging, including processes of in- and exclusion.
Although this academic and propositional view on belonging in care is dominant, it is in our view too detached from everyday experiences of people, such as those of Marcel. Rather, we propose a different kind of belonging, one that is based on an experiential and imaginary epistemology and includes both longing and belonging.
Departing from a particular and relational stance on care, we draw attention to the connection people experience with two worlds: one’s physical, “real” world and one’s proposed, imaginary world. By “real world” is meant: one’s everyday physical and material reality.
Those who care for a disabled loved one and those who are cared for, may experience this “real world” as rewarding, but also as challenging, as it involves hard work, endurance and perseverance. Consequently, the real world of giving care, as well as receiving care, can conflict with an imaginary or ‘proposed world’ (cf. Paul Ricoeur), where your dreams, longings and aspirations reside. Although this proposed world is imaginary, it is closely connected to our everyday reality.
In our group exhibit we honour and challenge this ambivalence between belonging to an everyday reality and imaginary longing, through the use of art. As Paul Ricoeur has noted: “(..) through fiction and poetry, new possibilities of being in the world are opened up within everyday reality. Fiction and poetry intend being, not under the modality of being given, but under the modality of power-to-be” (Ricoeur, 1981: 142). By viewing art as playing a central role in bringing about self-realization and a ‘power-to- be’, we hope to honour and bridge both worlds.

NL

Verlangen naar erbij horen
Onderzoekers presenteren in deze workshop via beelden, klank en andere kunstzinnige acts. Thema van onderzoek: de wereld waarin we leven en de wereld waarnaar we verlangen. Leven met een beperking, het samenleven met iemand met een beperking… mensen ervaren dit als iets moois, en iets lastigs, en iets uitdagends, en… De onderzoekers vertrekken vanuit deze verhalen om van hieruit na te denken over de rol van kunst in het realiseren van onszelf en onze kracht om te zijn wie we zijn.

O – 61

Collaboration in research

Henriëtte Sandvoort[1], Sofie Sergeant[2,3], Kim van den Bogaard[4] Elsbeth Taminiau [4]
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[3] Disability Studies in the Netherlands (DSiN), Amersfoort, the Netherlands
[4] Tranzo, Tilburg University, Tilburg, the Netherlands

Aim & Methods
The aim of the Dutch National Program of Disabilities (NPD) is ‘contributing scientific knowledge towards the full – and fulfilling – societal participation of those with a handicap or chronic illness’ (www.zonmw.nl). With this program, the funding body ZonMw strives to develop, disseminate and applicate knowledge to improve the quality of care for people with intellectual disabilities (ID). In striving to further the participation and inclusion of people with ID their involvement in the

execution of this program is essential. Therefore, people with and without ID will collaborate in research projects receiving a grant from the NPD. As requested by the funding body ZonMW, the aim of the study ‘Working together, learning together’ is to explore the effectiveness of this collaboration between people with and without disabilities on both the project level (e.g., with regard to implementation of project results) and the individual level (e.g., feelings of inclusion and participation). This project builds on previously conducted projects in which we explored competencies considered important in the collaboration between people with and without ID and participatory research methods.
Four people involved in the project ‘Working together, learning together give their insights in thissymposium. Photographs, clear text, film and speech guide us through this symposium.

NL

Samenwerking in onderzoek
Het nationale ZonMW programma Gewoon Bijzonder ontwikkelt en verspreidt kennis om ondersteuning voor mensen met een verstandelijke beperking, meervoudige beperking of niet-aangeboren hersenletsel te verbeteren. Binnen dit programma vindt ook het project ‘Samen werken, samen leren’ plaats. Hun insteek is: Hoe kun je deelname aan onderzoek door mensen met een beperking bevorderen?

Vier betrokken onderzoekers geven inzicht in hoe zij hun inclusief onderzoek en samenwerking zelf vormgeven. En hoe zij andere onderzoeksprojecten coachen en trainen. Hoe is het onderzoek ontstaan? Hoe wordt het vormgegeven? Wat levert het op voor onderzoek, voor de onderzoekers en voor de samenleving? Via woord, beelden, film en discussie lichten zij hun bevindingen toe.

O – 62

All the limbs we cannot see: a comparative reading of Michelangelo’s David and Berlinde de Bruyckere’s Into One-another III, to P.P.P.

Andries Hiskes
The Hague University of Applied Sciences, the Hague, the Netherlands

Aim & Methods
Berlinde de Bruyckere’s sculpture Into One-another and Michelangelo’s David could not be any more different. Into One-another presents us with an abstract and unclear body, while the David is perhaps the most famous body in (art) history. But what can we learn from reading these very different bodies for Disability Studies? In this presentation, I will argue how reading these sculptures impedes and problematizes the act of close-reading itself, and how this impediment allows us to rethink the terms ‘function’ and ‘aesthetic’.

O – 63

Documentary ‘Rollende moeders’ (‘Rolling Mom’s’)

Ymke Kelders
University of Applied Sciences (Hogeschool van Amsterdam), Research group Community Care Amsterdam, the Netherlands

Aim & Methods
This short-documentary scrutinizes the representations of mothers in a wheelchair in today’s (western) society. From a personal perspective and experience with having a mother in a wheelchair, the director of the film talks to mothers who raise their child from a wheelchair. What role does the wheelchair play in their mothering, how has this changed over the last 30 years? How do technological and medical developments influence the ways the role of a mother with a handicap is looked at, and what are the dominant images in society?
This abstract proposes a possibility to screen the film and have a discussion afterwards. I believe that the audience of this conference will have interesting and important views on this topic that can be of great importance for the discussion around this topic, and the ways the director

of the film can continue working on this theme. An example question could be: does this film show a productive representation of mother(s) in a wheelchair? How can we challenge the dominant discourse on mothers in a wheelchair and what images should be present in this? How does it relate to ‘the art of belonging’?

O – 64

Exploring 24/7 online support for people with intellectual disabilities

Miriam Zaagsma[1,2], Alice Schippers[2], Karin Volkers[1], Geert van Hove[2]
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Aim
Services for people with intellectual disabilities (ID) increasingly use E-health applications such as Telecare. The Dutch service provider Philadelphia Care Foundation implemented DigiContact as part of their support packages. DigiContact is an online videoconferencing program. Users can contact specially trained support professionals 24/7. It is aimed at promoting independence and community participation of adults with ID who live independently in their own homes. Through research we aim to get insights into the experiences with DigiContact support. We also want to know if the online support is effective in meeting the support needs of its users.

Methods
In this research project academic researchers work together with co-researchers. Last year we interviewed 21 DigiContact users regarding their experiences with the online support. Currently we are performing multiple qualitative case studies to investigate the role of the online support in meeting a broad variety of support needs. In the case studies we will also look at how DigiContact support relates to other forms of formal and informal supports.

Results
From the interviews we know that people contact DigiContact for a broad variety of issues. Important themes were mental health, social contacts, practical issues and physical health. The case studies are work-in-progress and the results will follow during the course of 2017.

Conclusions
Conclusions based on the first results will be presented at the conference. In our presentation we will also reflect on our experiences with doing research inclusively.

NL

Elke dag, elk uur, online ondersteuning
Voorzieningen voor mensen met een beperking kiezen steeds meer online hulpverlening. DigiContact is een voorbeeld hiervan. Hiermee kan je online contact hebben via stem en beeld (videoconferentie), op momenten dat mensen het nodig hebben. Deze vorm van ondersteuning wil zelfstandigheid en deelname aan de samenleving vergroten voor mensen die zelfstandig wonen.
In dit onderzoeksproject werken onderzoekers samen met co-onderzoekers met een beperking. In deze presentatie gaan de onderzoekers in op de waarde van deze ondersteuningsvorm. Onderwerpen als geestelijke en fysieke gezondheid, sociale contacten en praktische organisatie, komen ook aan bod.

O – 65

Mind mapping in reciprocal participatory research

Minne Bakker, Leendert van de Merbel
VUMC, Amsterdam, the Netherlands

Aim & methods
Data analysis is an crucial part of scientific research. In different types of analysis (e.g. thematic or grounded theory) mind maps are used to help the researcher structure the data. Mind mapping helps to visualize the structure of the data. If one of the researchers in a research team has a visual impairment (as in our team), it is needed to develop another kind of mind mapping, suitable to ‘visualize’ the data for both researchers with

and without the visual impairment. In our study we worked with Lego to make a tangible mind map. At the conference, want to present our Lego model and share our experiences with working with such a tangible mind map; what were difficulties, what are advantages? With use of our experiences with the model on the one hand, and knowledge about some existing forms of mind mapping on the other hand, we will discuss the usefulness of the model.
Designing this kind of tangible mind map contributes to more inclusive (reciprocal participatory) research methods. Participatory research / reciprocity / mind mapping.

NL

Samenwerken met een onderzoeker met een visuele beperking: Mindmappen met Lego
Samenwerken in onderzoek met mensen met een beperking is slechts mogelijk als we onze onderzoeksmethoden uitbreiden en meer toegankelijk maken.
Ook bij het analyseren van onderzoeksmateriaal moeten we op zoek gaan naar 'inclusieve onderzoeksmethoden'. Mindmaps kunnen helpen om je bevindingen te structureren. Maar hoe kunnen onderzoekers met een visuele beperking zicht krijgen op deze mindmaps? Onderzoekers Leendert van de Merbel en Minne Bakker gebruiken Lego-blokjes om een tastbare mindmap te maken. Beide onderzoekers bespreken de voordelen en de toepasbaarheid van deze methode.

O – 66

A joint venture: persons with a disability, their representatives and researchers working side-by-side in scientific research projects.

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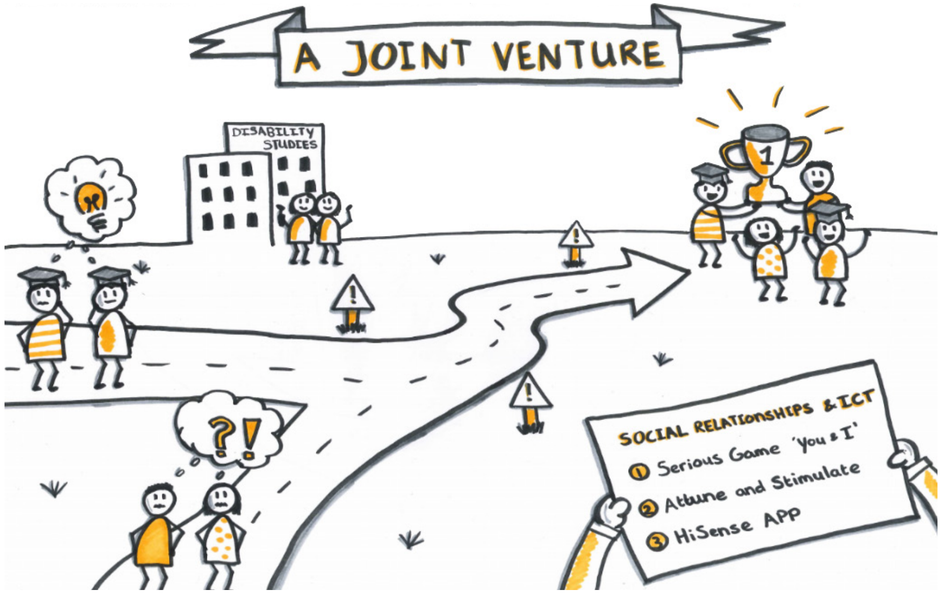

Aim & Methods
The aim of this workshop is to exchange experiences of persons with a disability, their representatives and researchers working side-by- side in a scientific research project such as in the project 'Interpersonal relations and ICT'. The largest gain in working together is that every participant contributes to research in his/her own unique way. We will highlight our

experiences starting with describing the collaboration in three different projects (micro-level). The first project is the serious game ‘You & I”, aimed at promoting the mentalizing skills of persons with intellectual disabilities or with learning difficulties. Second, the development of a checklist called ‘Attune & Stimulate’, for parents and caregivers of persons with severe multiple disabilities. Third, an app ‘Hi Sense’ for parents and caregivers of persons with a moderate to mild intellectual disability. Then we focus on working side-by- side in all the projects of ‘Interpersonal relations and ICT’ (meso-level). For this purpose four persons with a disability and the researchers received training in research collaborations. Finally, we will focus on the participation of others, such as researchers from Disability Studies Netherlands (macro-level). During the workshop the participants are welcome to share their thoughts and inspiring ideas that can contribute to moving forward in collaborative research.

Niets over ons zonder ons: Mensen met een beperking, hun familie en onderzoekers werken schouder-aan-schouder in onderzoek

Het nationale ZonMW programma Gewoon Bijzonder ontwikkelt en verspreidt kennis om ondersteuning voor mensen met een verstandelijke beperking, meervoudige beperking of niet-aangeboren hersenletsel te verbeteren. Binnen dit programma vindt ook het project ‘Sociale relaties en ICT’ plaats.

In het onderzoeksproject ‘Sociale relaties en ICT’ zijn mensen met een beperking, hun familie en onderzoekers betrokken als onderzoekers. Mensen met een beperking werken mee in het onderzoek vanuit hun ervaringskennis. In deze workshop worden de ervaringen in deze samenwerking gedeeld en besproken. De schouder-aan-schouder-samenwerking vindt plaats in drie deelprojecten: het ontwikkelen van een app voor mensen met een beperking, een checklist voor ouders en ondersteuners van mensen met een beperking en een app voor ouders en ondersteuners.

O – 67

Moving Thought: currents in the hidden choreography in our lives

Trude Cone
Amsterdamse Hogeschool voor de Kunsten, Amsterdam, the Netherlands

Aim & Methods

The workshop focuses on early movement patterns and how they form the base for perception and ultimately decision-making processes throughout the lifetime.

Initially sequential, our movement vocabulary expands, enabling us to organize and interact in a complex world. In the workshop we will explore early movement patterns and address belief systems around movement and how underlying principles of movement (for instance time, space, speed, order of action) are first learned through movement and then become part of our thought processes and our individual ways to deal with our social and physical environment.

The workshop focuses on three stages of early primitive, inherent movements that remain active as the foundation in our movement alphabet:

1. Embryological forces build the body.
2. Primitive reflexes in utero activate a sequence of movement that will allow later for flexibility and ease.
3. After birth, developmental movement patterns enable our interactions to become increasingly independent.

The goal is to get static processes in motion again by revisiting early patterns, and uncompleted development. Workshop participants will experience these early movement patterns, how they contribute to a feeling of embodiment and the role they play in usefulness in communication, organization, planning and creating environments. Starting these processes at any age can improve the quality of life. Within the context of nonverbal or creative arts therapies the work can be used as assessment as well as base for intervention

Hoe wij bewegen is verbonden met hoe wij kijken en kiezen

Deze workshop kijkt naar hoe wij bewegen, al van kleins af aan. Onderzoeker en danser Trude Cone legt uit hoe onze manier van bewegen invloed heeft op hoe wij kijken naar de wereld en hoe wij keuzes maken in ons leven. Hoe wij denken en reageren zit dus in onze manier van bewegen. Dit ontdekken we in deze workshop via dans en gesproken taal.

Stream: Inclusive Education & Work

O – 68

Educating Ronald

Ronald Kloet, Ariene van Westen,
Philomene op 't hof
Space Station, Zierikzee, the Netherlands

Aim & Methods
The demonstration will be kickstarted with the three minute inspirational video – Educating Ronald – that shows how sensory learning combined with drama and poetry can open a whole new world for adult students whose lives are illuminated by a profound disability. During the demonstration, participants will be invited to step out of character and play the role of Ronald. The demonstration combines magical moments of sensory stimulation and creative drama with experiences of light and darkness. The demonstration ends with an epiphany that reveals the hidden meaning of profound disability. The aim of Space Station is to educate. The mission is to mainstream. The focus is on human rights. All three aspects are woven together in this demonstration. Health permitting, star of the video, Ronald Kloet, will co-lead the demonstration. With his faint voice and faltering steps, he points the way towards a deeper intelligence, a profounder understanding and a greater questioning of what it means to belong.

Leren van Ronald
De demonstratie start met een film. Deze film heet 'Het opvoeden van Ronald'.
Deze film toont ons hoe zintuiglijk leren, theater en poëzie een nieuwe wereld kan openen voor volwassenen met een ernstige verstandelijke beperking.
In deze workshop zal je uitgenodigd worden om de rol van Ronald op te nemen. Tijdens de demonstratie maak je magische momenten van zintuiglijke prikkeling mee. Daarnaast maak je creatief theater mee met ervaringen van licht en donker. We eindigen met een hoogtepunt waarin we inzicht geven in de verborgen betekenis van de ernstig verstandelijke beperking.
Het doel van SpaceStation is mensen tot inzicht brengen. De focus is op 'belonging' en mensenrechten. Tot inzicht brengen, inclusie, belonging en mensenrechten zijn verweven in deze workshop. Ronald Kloet is – als zijn gezondheid het toelaat – aanwezig tijdens de workshop als co-leider. Hij toont ons met zijn stem en beweging de weg naar een diepere vorm van intelligentie, een beter in vraag stellen en een beter begrip van wat het betekent om erbij te horen.

O – 69

Impact of participation in academic friending courses on individuals with disabilities

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Aim
In most Western countries, legislation and policies concerning persons with disabilities advocate for their full social inclusion and community participation. Within the education setting, a steady movement can be seen in many Western countries from segregated schools to inclusion of children and youth with disabilities within the general education system. However, across many Western countries, including Israel, fewer opportunities exist for inclusion of persons with disabilities within higher education, e.g. colleges and universities. In Israel, a recent project entitled "Academic Friending" (led by Israel-Unlimited) allows for individuals with disabilities to study within an academic course side-by-side to students without disabilities. Within these courses approximately half of the students are with disabilities and the other half without disabilities. These courses allow students with disabilities to have a taste

of university experience and allow for mutual contact between students with and without disabilities.

Methods

Participants in this study are non-for credit university students with disabilities who study within these courses during the 2016-2017 school year. This mixed methods study includes qualitative interviews and focus groups conducted at the end of the course, quantitative questionnaires collected before and after the course and observations conducted within class sessions.

Results

Results presented will focus on the impact of participation in Academic Friending courses on students with disabilities. Specifically, results will focus on the experiences of students in terms of relationships developed with other students, learning experiences, as well as difficulties faced. Further, we will present results related to implications for the self-esteem and identity of students with disabilities. Finally, we will present results regarding necessary accommodations that aid in the success of inclusion within higher education.

Conclusions

Results will be discussed in light of recent laws advocating for greater inclusion within higher education. We will discuss insight gained from the current experience and how this experience can be extended to additional university settings.

O – 70

Adequate education and adequate occupation. What is adequate in the social environment of youth with a disability?

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Aim & Methods

For the last years, transitions took place in the Dutch legislation on adequate education and adequate occupation for people with disabilities. In general, all this transitions do have the consequence that people have to be capable of telling what support they need. Due to austerity policies and changing perspective on the methods on helping, people are primarily supposed to ask their informal network to give support, before professional support can be activated. Also, the need to provide demand-driven support is increased by this changes. The question that is being addressed in this research is ‘what are the experiences of adolescents with disabilities on receiving professional support during education or in (finding) work?’. The method that is used is an analysis of 35 narratives, that are made by student researchers. The narratives have been categorized based on their quality and the transcripts have been coded based on the three sub questions: 1. What are the experiences on the given support by educational professionals, social workers, care takers and job coaches? 2. What are their experiences on informal support? 3. What do adolescents with disabilities expect about the support they need in the future on education and work? In general, extra attention had been given to the personal encountering or undergoing of their experiences.

Results

Based on the 35 narratives, the impression of the researchers is raised that the way adolescents with disabilities are treated in education and in finding work is merely based on the view the professional has of their situation instead of the view the adolescent itself has. In the narratives, many point of views of professionals on their situation are told by the adolescent, and the impression is given that the support they get is based on that opinion instead of their own desires and needs. Another result of the analysis is that the perspectives the adolescents have on their future, are merely the same as any other adolescent has. A job, a house, a partner. What support is needed to reach their goals is not easy to say for them. The need to experience at first what support is needed, is addressed a few times in the narratives.

Conclusions

The conclusion in general is that the client centered approach that is needed to give successful support to this adolescents isn’t every day practice in supporting adequate education or adequate work.

O – 71

School and social participation for children with disabilities: What happens when ethnicity and migration also come into play?

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Aim & Methods

In recent years increased emphasis has been placed on creating personalised living options for people with intellectual disabilities in contrast to the congregated arrangements of past decades. Supports for independent living embody the aspirations of the Convention on the Rights of Persons with Disabilities for greater choice and community participation. To date though, there is sparse evidence internationally as to the outcomes for tenants in personalised living arrangements, particularly with respect to their social inclusion. This qualitative study examined the experiences of 34 persons in Ireland who had moved from congregated residential provision to more personalised accommodation and support arrangements. Individual interviews lasting on average 45 minutes were conducted with the main support worker (n=31), the tenants (n=21) and, when available, relatives who had regular contact with the tenant (n=13). Interviews were conducted in the tenant's home and, on average, two years after persons had moved to their new settings which typically took the form of rented accommodation in town settings with visiting staff for a number of hours per day. Interviews were audio-recorded and were transcribed word by word. Two authors initially undertook thematic analyses separately on a selection of transcripts. Discussion of emerging themes and sub-themes with the other two authors allowed for development of shared meaning. Themes were triangulated across the three informant groups. Personalised living had resulted in greater community participation and a widening of tenants' social networks. The support workers played a significant role in helping tenants to reconnect with their family and with people in the community whom they had known previously.

Results

Joining existing community groups helped new friendships to develop. However there was sparse mention of romantic relationships developing or of people gaining paid work. Concerns were expressed – mainly by relatives – of people being isolated in their home and the sustainability of the personalised arrangement if people required extra support. Personalised living arrangements were effective in facilitating greater social inclusion of tenants but this required significant transformation in the role of support workers, the building of trusted relationships and increasing the self-confidence of tenants.

O – 72

Transforming vision into useful policy for all students in higher education

Judith Jansen, Nanne Roos Vonk
Expert centre handicap + studie, Den Bosch, the Netherlands

Aim & Methods

Good policy helps to achieve high quality education for students with disabilities. Many universities and universities of applied science in the Netherlands organize their educational program based on a medical model. Adjustments to this program can be made individually at the request of the student.

Our ideal is flexible education. Diversity would then be the norm in education. This demands a learning environment in which all students can learn time and place-independent, according to their educational needs.

To help universities transforming this vision of diversity into useful policy, we have developed two different scans: a Policy scan+ and a Flex scan. In this workshop you get to know these scans. We will discuss your situation according to the usefulness of either of these scans. How can we stimulate an educational transition from a medical model to a more flexible one, so that students encounter less obstacles?

O – 73

Ethical Dilemmas of Teachers with Physical Disabilities for Integration into Schools

Noa Tal-Alon, Orly Shapira-Lishchinsky
Bar-Ilan University, Ramat-Gan, Israel

Aim & Methods
Ethical Dilemmas of Teachers with Physical Disabilities for Integration into Schools Teachers with disabilities have a professional advantage in working with children who are perceived as different (Dvir, 2013). There are only a few research studies that have focused on the difficulties and dilemmas of teachers who have different disabilities (Duquette, 2000). This research has broadened the knowledge and understanding of the ethical dilemmas of teachers with physical disabilities such as blindness, deafness, mobility disabilities, and medical disabilities. It is part of a doctoral dissertation exploring the ethical dilemmas that arise from the employment of teachers with physical disabilities from the perspective of school principals, colleagues, and the physically disabled teachers themselves. The study sample included 16 teachers with different disabilities. This particular study was conducted using a qualitative approach through the Narralizer computer program based on a series of in-depth interviews. The data analysis was carried out by grouping major points of interest into specific categories and sub-categories.

Results & Conclusions
The findings of this research suggest that teachers with disabilities struggle with three major ethical dilemmas concerning their integration in school:

- Coming-out- of-the- disability-closet dilemma – whether or not to reveal their disability to the school staff.
- Classroom management dilemma- how to conduct a lesson without letting the disability interfere in any way.
- Equality dilemma- should one try to appear “like all the other teachers” or take advantage of the legal rights regarding handicap accessible facilities.
- The different dilemmas that teachers with disabilities deal with give insight into their difficulties in integrating into the school system, as well as their strategies to improve integration.

The importance of this research is in its potential to influence policy decisions that may be implemented by the Ministry of Education regarding a support system for both new and veteran teachers with physical disabilities.

O – 74

The pursuit of belonging: insider perspectives on the meshwork of participation in education

Hanne Vandenbussche, Elisabeth de Schauwer
Ghent University, Disability Studies and Inclusive Education, Ghent, Belgium

Aim
The UN Convention for the Rights of Persons with Disabilities (UNCRPD, 2006) states full participation should be premised for all people with disabilities. Forthcoming, all children with special educational needs (SEN) have the right to take part in the regular educational system. However, what is meant by ‘full participation’ is not clear. In this presentation, it is argued that the clarification of the meaning of participation is essential to transform education in a welcoming context for all children. An educational system has the potential to open up possibilities to realize full participation or/and to close them down. Pupils with SEN have the desire to connect with a complexity of other people. Embedded in a context characterized by a variety of connections, they participate and belong. At the same time, they experience discrimination and exclusion.
The aim of the study is to unravel the meaning of ‘full participation’. Full participation is not seen as a state of being, but as a process of becoming.

Methods
Three focus group dialogues (Kjellin, 2008) were organized. Each focus group dialogue was composed heterogeneously out of 4 participants. Every group was assembled with one mother of a child with SEN, one self-advocate, one friend or sibling of a person with SEN, and one personal support worker of a pupil/student with SEN. In The participants shared stories about how and where they see full participation ‘at work’.

Results & Conclusion
These narratives demonstrate how ‘full participation’ is relationally being formed inside and between the many connections pupils seek in order to ‘belong’. The concept is multi-layered and closely connected to accessibility in a relational sense. ‘Full participation’ is not easy to grasp because of its emergent and entangled nature. Since moving contexts require moving definitions, a fixed meaning of the concept is not desirable.
In its transformational character, it becomes clear that full participation is about belonging, with an important emphasis on complex interconnectivity, less conditionality and imagination.
Keywords: ableism, participation, belonging, inclusive education

O – 75

Roundtable: disability Studies in curricula of Universities of Applied Sciences: how?

Mieke Cardol
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Person-centred care as well as shared-decision making in health care and the social domain ask for professionals who value experiential knowledge of people with chronic conditions and who can integrate experiential knowledge with their professional knowledge and competencies.
However, current curricula at universities still are largely based on medical paradigms and epidemiology. Students are trained to become the expert, in a way that often collides with person-centred care. Disability Studies in the curricula can provide upcoming professionals with new valuable knowledge, competencies and the reflective skills needed.
But how to implement Disability Studies, and in which curricula?

In this round table, while using an interactive working form, we will share experiences, dilemma’s and future dreams with regard to Disability Studies in the curricula of Universities of Applied Sciences. The case of Disability Studies in Rotterdam shows that professionalization of lecturers of several educational directions is essential. Also, taking questions of educational managers or lecturers as a starting point, providing scientific evidence for the need to implement new knowledge and competencies in the curricula, as well as developing small multidisciplinary projects and setting up a minor that incorporates the basis of Disability Studies are helpful.

The aim of this round table is to establish an inspiring overview of best-practices and conditions that will make Disability Studies work at universities. Further, we also hope the roundtable will be the start of a new network in which ideas and practices can be shared, also beyond the conference.

O – 76

Studying English and Dutch personal accounts from a Critical Autism Studies perspective

Hannah Ebben
Autism Centre, Sheffield Hallam University, Sheffield, United Kingdom

Aim & Methods
As a Dutch Autistic research student, I feel at home at my British university and its unique approach to autism. The Autism Centre does not focus on the cause of autism or autism interventions. Its staff is primarily interested in the rights of autistic people and their families. I do not study disability as a disorder in people’s bodies too. I think that it is important to research disability as a form of social injustice. We can make the world more accessible for disabled people and make society more inclusive. Some autistic people come together to have a sense of social belonging and to share their thoughts on social justice. Many of them tell that they would like to have their voices heard. Most people who talk about autism in public are experts on the topic. However, they often do not have the label of autism. They presumably do not personal experience disability-based injustice. I am more interested in biographies and documentaries from people who identify as autistic. At the Autism Centre, we call these ‘personal accounts’. I am interested in the way our culture works and the history of things that we think of as ‘normal’ now. The term ‘autism’ has been described in many different ways by many different people.
In the recent past, scientists thought that autistic people are not capable to voice themselves. In our present day, there are people who identify as autistic and do publicly talk about their lives. My presentation will expound my argument that past beliefs on autism are still perceivable in contemporary personal accounts.

I will speak about a few documentaries of and videos from people who openly identify as autistic. I then argue that my aim is not to decide whether these depictions are 'true' to reality or not. I will give a Critical Autism Studies perspective and show that the personal accounts are part of a society in which it is normal to doubt people when they say that they are disabled. I then defend the use of creative and participative methods as a way to facilitate belonging nevertheless.

O – 77

Experience of the KIKESA Center in the field of rehabilitation: assessment of 50 years.

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Centre Professionnel pour Handicapés KIKESA, CPH-KIKESA, Kinshasa, Democratic Republic of Congo

Aim & Methods

At the dawn of its 50 years of existence, what experience has the Kikesa, Professional Center for Disabled Persons whose main mission is the global rehabilitation of the handicapped person?
In terms of training, the population of motor deficiencies was in the majority in the first decade. The other categories were timidly registered as of the 3rd decade, including inadequate schoolchildren, children with cerebral palsy and intellectually impaired persons, hearing impaired, although in the first few decades, Of the fourth decade. The last two decades have been marked by a large number of inadequate schoolchildren and hearing impaired.
In the finalists' registers, more people with motor deficiencies had to complete their vocational training for four decades. The section of cutting and sewing sparked and presented the greatest number of finalists from the second decade.
The number of staff has increased from 2 persons to 89 in the last decade. The presence of disabled staff was effective from the beginning with a larger number of men.
It follows from this experience that people with disabilities or not, all feel the same needs. Education and training remain the two keys to the development of mankind. The care of people with disabilities is characterized by high costs of special care and appropriate training. On the other hand, it is clear that in the Democratic Republic of Congo, the number of rehabilitation structures and qualified staff is insufficient. From the perspective of the future, it is imperative to see the Kikesa Center as a center of attraction and individual and collective outreach for rehabilitation actors. It will be a question of organizing the activities so that the service rendered to the disabled refers to the frames and the parents a just return. In other words, work around the handicapped person that leads to the development of all in a globalizing perspective.

O – 78

Autism Ambassador: Impact on workplace by contributing to inclusiveness and diversity.

Lujan J. Blankenstein-Van der Veen
Autism Ambassador "Vanuit Autisme Bekeken", Varsseveld, the Netherlands

Aim & Methods

Autism has impact on all aspects of life, also in the workplace. Autism involves talents and qualities that can be of great value in organizations. Behaviour, as a result of autism, is often misunderstood.
What is needed to make those talents and qualities visible and accessible is a healthy working environment in which people with autism can function optimally. Furthermore, an open work-environment where employees dare to say they have autism. And time for employees to get to know each other and to enter into dialogue to gain a better understanding of autism in the workplace.
Autism Ambassadors are employees with autism, working in large organizations. They want to raise public awareness of autism by engaging into conversation with employees and employers, using their own personal experiences. This leads to better recognition and acknowledgement of autism in the workplace. Thus, better understanding is created between employees and greater awareness of the importance of recognition and acknowledgement of diversity in full width. Autism Ambassadors can create room for open conversation, increase mutual understanding and this leads to a better working environment. They can contribute to create a framework for all employees to function properly within an inclusive corporate culture.
The Ambassador Model provides large employers a handle to work sustainably on inclusiveness and diversity at the workplace. If people with autism in your organization can become visible, this can be of

great value for the development of a more inclusive corporate culture. Within the right context, an active Ambassador in the organization allows other employees also to be open about their autism or other non-visible vulnerabilities. Openness allows organizations to better understand diversity and embrace it. With regard to individual qualities, talents can be made to use and create support for diversity: focus on talents, not on limitations. Ultimately this policy reduces stress, reduces sick leave and, above all, it leads to more enjoyable work, for all employees.

O – 79

Young persons with health conditions: measures on prevention of disability benefit and activation.

Edwin Luitzen De Vos, Rienk Prins, Tobias Carstensen, Sara Hultqvist, Michael Fuchs, Sarah Woodin
CHAMP R&C, Amsterdam, the Netherlands

Aim & Methods

In 2016 we worked on a comparative study on measures to reduce the growth of the number of young persons depending on disability benefits. This resulted in a batch of reports on disability insurance in five European countries and an overview of selected reforms, experiences and lessons. These were prepared for the government of Switzerland. The reports focus on national efforts to prevent disability applications by young people in Denmark, Sweden, Austria, United Kingdom, and the Netherlands and an overview comparing the reforms.
In general, the reports show that mental impairments among the young are on the rise across Europe and that governments are responding with a wide variety of reform approaches. They also show that, despite considerable effort, no country has yet succeeded in reversing this trend through promoting
employment.
Commissioned by FSIO (Federal Social Insurance Office, Switzerland) experts from five countries described reforms and other measures that had been taken nationwide to prevent and reduce benefit dependency in this target group. Reforms and measures vary from age barriers for claiming disability benefit, or earlier intervention (e.g. during sickness absence) and social inclusion, to counselling of workers and employers, or better accessibility of mental health care.
For the countries included the backgrounds and elements of reforms have been systematically described, including conclusions from evaluations on implementation, impact and lessons learned.

The synthesis report summarizes the reforms (in “fact sheets”) and discusses national findings and conclusions as well as the role of contextual factors (e.g. political), ongoing developments, etc.
FSIO made the reports available on its website. The press release (in German language) including links to the reports (incl. summaries in 4 languages) can be found in:
https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-66110.html

O – 80

Associations between multiple problems, work status and perceived health among disability beneficiaries

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Aim

Disability benefit recipients face participation problems related to functional impairments due to ill- health. Many of them have additional disadvantages, that may reinforce disability and ill-health, hampering participation and return to work. This study aims to investigate nature and severity of multiple problems (MP) in a population of disability benefit recipients, whether MP are associated with work status and whether this association is influenced by perceived health.

Methods

Cross-sectional analysis of a sample of 209 disability beneficiaries in the Netherlands. Participants with (partial) work capacity were recruited by labour experts (LE) from the Social Security Institute: the Institute for Employee Benefits Schemes (UWV). With a 10-item self-report questionnaire we assessed the presence (yes/no) of MP, categorized as psychosocial (e.g. poor health), cultural (e.g. low education), economic (e.g. financial problems) or normative (e.g. contact with police), and whether participants experienced barriers (none/mild/moderate/severe) for societal participation and work due to any of the reported problems. We used the 12-item Short Form to measure perceived health. We included a single-item question on work status: 'Do you have paid work at the moment?' (yes/no).

Results

The sample consisted of 209 persons (mean age: 36 yrs; SD: 13.0). In the total sample 83.2% of participants had no paid work. The prevalence of MP was 86.0%. Psychosocial problems were reported in 93.3%, cultural problems in 71.8%, economic problems in 46.4% and normative problems in 6.2% of all cases. Severe barriers for societal participation and work were primarily reported in relation to psychosocial and cultural problems. MP were significantly associated with negative work status. Perceived health had no moderating or mediating effect on this association.

Conclusions

Disability benefit recipients with MP are less likely to have paid work as compared with those without MP. Despite the high prevalence of severe barriers due to psychosocial problems, the association between MP and negative work status is independent of perceived health. Interventions to improve work participation of disability benefit recipients with MP should be directed at non-health related problems, i.e. cultural or economic problems.

O – 81

The Autism Embassy: the autistic colleague acting as a change agent at work.

Diederik Weve
Vanuit Autisme Bekeken, Shell, Den Haag, the Netherlands

Aim & Methods

How many of you know an autistic colleague that seems to be functioning normal or good at work?

Many disabilities are invisible at the workplace and remain so when persons choose to pass as normal because they know how to compensate or disguise. While needs related to disabilities remain hidden they are difficult to negotiate, the full potential of individuals and teams may not reached and the conditions under which results are achieved are likely to be more stressful. For disabilities it is a challenge to match the inclusivity as attained for gender, race, culture.

The Autism Embassy is a concept where an autistic employee acts as a role model being open about his needs and strengths (the Ambassador). He/she is facilitated by network of colleagues (the Embassy). Being visible and engaging in activities like giving workshops, blogging, answering questions or helping HR gives colleagues the opportunity to normalise interactions and feel comfortable doing so. In 2014, the Autism Embassy was started as a project sponsored by the Dutch Ministery of health. It has since trained 18 Ambassadors in 15 large organisations in industry,

banking, health care and public services. Together, they reach over 500,000 employees in the Netherlands.

Success of the Embassy relies on a combination of three factors: 1) an organisation that fosters and supports diversity initiatives, 2) an autistic individual who wants to disclose and learn to engage and 3) colleagues that give support (e.g. organising a room and an announcement).

The fourth factor is not obvious, being implicit as in many human interactions: it is a sense of belonging. Many individuals will have had experiences with disabilities in their personal life and have integrated this in their life as normal. Encountering a disability at work then may provide the opportunity to bring a little bit of society into the workplace. Where most of the colleagues feel it belongs. An appeal for normalisation by a colleague may invoke a stronger response than that by an outsider.

Diederik "Engineer by birth, autistic by diagnosis" tells about the project, and the sensation of belonging.

Stream: (Family) Quality of Life

O – 82

The art of signing: generational differences in Deaf people's signing practices

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Aim & Methods

In most countries in Europe and the US, deaf people were forbidden to use sign language until well into the 20th century. It was considered a primitive means of communication and signing deaf people seen as 'not fully human'. Deaf children grew up having to learn to produce spoken words and 'read lips' in order to acquire spoken language, an strenuous and often futile activity. In the 1960s linguists showed that sign languages are 'real' languages, a claim which supported another perspective on deaf people: that of a cultural community.

In The Netherlands conflicts between sign language protagonists and those adhering to the so called 'oralist approach' dominated deaf education until the 1980s. Deaf emancipation, the struggle for rights and cultural recognition evolved in tandem, but deaf people who have grown up with the oralist philosophy, were often caught in between these very different views on deafness. Brought up with the notion that signing was a forbidden and inferior way of expressing oneself, deaf people who are now at a more advanced age, often still have a biased view on using sign language. Moreover, because of the prohibitive environment in their younger years, they regularly lack the command, fluency and wealth of vocabulary young deaf signers have today. The embodied communicative practices of these elderly thus bear the traces of this conflicted history. Young deaf people on the other hand, are proud of their Deaf identity and for them signing is a statement of belonging to a culture with its own history and practices. They see sign language not as a mere communicative tool, but as a rich language in which they can think, dream, talk, whisper and shout… and express their deepest emotions in poetry and raps.

In this film project, different aspects of belonging to the deaf community are addressed in the imagery. An edited sequence of the central discussion between the two main protagonists in the controversy over the use of sign language is framed by footage of signing and non-signing hands of elderly deaf people and by the fluent, proud signing of deaf rappers.

O – 83

The grace of motherhood: Motherhood and (family) quality of life in Ethiopia

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Aim

The findings of this study indicate interconnectedness between several life domains including family and social interactions, and emotional, physical, and material well-being. These life domains are conceptualized in (family) quality of life constructs that reflect a sensitizing approach to various challenges and provide a framework for understanding disability and motherhood.

The purpose of this study was to explore the experiences of women with disabilities by focusing on their need for intimacy and marriage, how they enjoy their pregnancy period while also facing challenges, and how they manage their motherhood responsibilities and take pride in them. We analyze how social roles and expectations present additional challenges. Moreover, the article identifies and documents experiences of intimacy and marriage, pregnancy and giving birth, and motherhood experiences of women with disabilities in Ethiopia.

Methods

This study used a qualitative methods that relied on data obtained from face-to- face interviews.

The primary instruments were in-depth, semi-structured interviews and personal observations, which allowed exploration of the full experiences of participants' own points of view as told in their own words. Thirteen employed women with physical or visual disabilities were participated in the interview, and the interviewees were from the Addis Ababa metropolitan area, Ethiopia.

Results

In the Ethiopian context that the family quality of life domains that are related to the three themes of this study – parenthood and disability-related support – have impact on the majority of the interviewed women with disabilities. This is mainly due to the socially constructed beliefs – the domain of influence of values – that disabled women do not fulfill the requirements of being wives and mothers. On the one hand, the interview results showed that women with disabilities believe that being intimate, pregnant, and mothers contributes to their quality of life.

Conclusions

The study contributes to understanding the grace of motherhood of women with disabilities of the world. First and foremost, our interviewees find agency, resilience, and pride in their experiences of intimacy, pregnancy, and motherhood. This enables them to face physical and material challenges, negative societal expectations, and hardships.
By sharing their experiences, women can empower and help each other.

O – 84

Experiences of fathers of children with disabilities: a forgotten chapter in family research?

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the 'Fathers Research Project'

Aim & Methods

Following McKnight (2015, 10) – we paraphrase her analysis and call – :… a wealth of literature has been conducted exploring the experiences of parents who have a child with a label/impairment. However, studies have been mainly quantitative in nature and have focused predominantly on mothers. This poses an issue because fathers can make important contributions to the development of their children. Understanding their experiences may improve support organized for both children and families. There is definitely a need for future research focussing and exploring the lived experiences and perspectives of fathers who have a child with a label using qualitative methods, as neglecting fathers in research and practice is worrying and potentially detrimental…
Disability Studies researchers from different European countries met a year ago and started to build a collection of fathers stories. Fathers of children with a label/impairment were asked to share videoclips of their children as a start to participate in pilot-interviews about their fathering experiences, their dreams and hopes for their children.
In this paper we present at one hand a rhizomatic analysis (Deleuze and Guattari, 1987) of the first collection of 'pilot interviews'. On the other hand we want to share a first attempt of a meta-ethnography (Britten and Pope, 2012) based on a systematic literature review as prepared by Jarlam Chen under supervision of Dora Bjarnason. (2017)
With the above described two entrances we hope to move back and forth between the stories we collected and the material as described in the small amount of available research literature following the tradition of the 'naturalistic retroduction' (Van Hove et al., 2009). This should bring us to an emergent 'second level' moving beyond the individual cases .

O – 85

Growing up with a sibling who is deaf/hard-of- hearing like myself

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Aim

The purpose of the current study was two folded: (1) to explore deaf and hard-of- hearing (D/HH) young adults' idiographic experiences of growing up with a D/HH sibling; (2) to explore the meaning of these experiences to D/HH individuals' sense of self and identity formation. Sibling relationships are very important in the lives of children and adults. Sibling relationships were found to influence children's psychological well-being, self-esteem, and the development of social skills (Milevsky& Levitt, 2005; Dunn, 2007). Moreover, sibling relationships provide a powerful source of support in adulthood

(Feinberg et al. 2012). In the field of disabilities, researchers have mainly questioned the impact of having a sibling with a disability on a none-disabled sibling. However, there is scare research on sibling relationship from the perspectives of siblings with disabilities, and especially when both siblings have a disability. Today many D/HH children are attending mainstream educational settings where their classmates are hearing.
In addition, within the family context, the majority of D/HH individuals are born to hearing parents. The presence of a D/HH sibling can therefore play a meaningful and influential role in their lives.

Method
In-depth interviews were conducted with ten young D/HH adults (20-30 years-old).Participants were asked to describe their relationship with their D/HH sibling since childhood and how the relationship influenced their coping and identity. Interviews lasted about an hour and were subsequently analyzed using Interpretive Phenomenological Analysis (Smith & Shinebourne, 2012).

Results
Five superordinate themes were identified, including: The role of deafness in either promoting closeness and support or conflicts and alienation within sibling relationships; The contribution of the siblings' relationship to identity formation and coping in a hearing environment; Processes related to explicit communication or none-communication about deafness and interactions within the family system; And ongoing changes in the relationship across the life-span.

Conclusions
The study's findings point to the complexity of having a sibling with a similar disability and the potential contribution of these relationships to the development and well- being of D/HH individuals, especially in familial and social environments that encourage 'overcoming' the disability. Findings reflected underrepresented psychosocial needs of mainstreamed D/HH children.

O – 86

RE-TOUCH Narratives of siblings

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Ghent University, department of
Special Needs Education,
Disability Studies, Ghent, Belgium

Aim & Methods

My presentation exists of two parts:

1. Shortfilm 'Lode's Code' (12 min.)

'Lode's Code' is is an auto-ethnographic research about the fragile relationship of the researcher's older brother Lode, and her own position within the family nest. Her leaving is the common thread. This hybrid animation-documentary is not meant for giving explanations about ‹the code› , rather subjective experiences are front of mind.

2. Work in progress monoprints 'Re-touch'

'Re-touch' is a follow-up project of the film Lode's Code. The focus of this project is the sibling-relationship in family's with a disability. By means of monotype prints based on interview material of siblings Marieke tries to reveal the hidden in family cultures.

O – 87

Flourishing: Training program for professionals and parents of people with severe disabilities

Janny Beernink, Mia Nijland.
Quality of Life Centre, Wijhe, the Netherlands

Aim

The curriculum ‘Quality of Life’ is a trainings concept for parents and professionals who work in education and care. The training is organized interdisciplinary. It is a learning process to come to a mode of operation and an approach of action to come to a more flourishing life. We learn from and with each other!

Methods

The intervention offers an alternative method in which people with severe disabilities get the opportunity to flourish and live a life that is in harmony with a dignified life. A worthy life as a starting point of care requires a different way of working: a narrative way of working.

This means thinking from the individual, thinking in possibilities, thinking outside existing systems and structures and where people with severe disabilities are seen as human beings.

This way of working is possible by listening to the story of a person and his life-environment.

It gives insight into how a person is treated and approached.

A narrative way of working requires a narrative way of thinking, a narrative way of listening and a narrative way of acting. The focus is on qualities, attitude, skills and values of the person, his relatives and professionals. It is a learning process of improving and changing.

It is a form of powerful intervention that creates space to take steps that fit what is important for a person and what a person really can do and can be (Nussbaum, 2006).

It is a working method for a better cooperation within and between care, education and parents and to come to an appropriate care and education offer. It is based on the evidence-based program of Carla Vlaskamp.

A persons profile is based on the current situation of the person and his care and education arrangement towards a holistic person image.

New skills are learned and applied in practice. The question and the needs of the person are systematically surveyed. Based on this, the assistance that is actually needed is required for the implementation of the day and week program. This takes place on the basis of dialogue and reflection as working methods.

O – 88

Training support staff to promote self-management in people with intellectual disabilities

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Aim

People with intellectual disabilities (ID) have increasing difficulties managing their own affairs.

Therefore, they often have to depend on others. This study investigated whether training support staff to promote self-management in people with ID, improved the level of independence of people with ID, while reducing their support needs and challenging behavior.

Methods

A training was provided to 28 staff members, working with 15 adult clients with ID who were living within a residential setting. The comparison group consisted of 11 clients with ID, living at the same organization, whose support staff was not trained. Effectiveness of the training was assessed with questionnaires addressing clients’ independence, support needs and behavior. These were filled in by staff members before the training and 3 and 6 months later. Additionally, 6 months after the training, focus groups were conducted with 13 trained staff members to evaluate the training.

Results

The intervention group showed a significant improvement in independence on the long-term, in contrast to the comparison group. On the measures for support needs and behavioral problems, no effect of the training was found. Although trained staff members reported limited benefits of the training, they had noticed some changes after the training in their own attitude, awareness and method of working.

Conclusions

Further research is required to study how self-management can be promoted more effectively in people with ID. In order to be more effective, the content, format and implementation of a training should be carefully considered, for example by paying more attention to its application to daily practice and including coaching-on- the-job.

O – 89

Those who care, need to belong as well – young carers

Rick Kwekkeboom
Amsterdam University of Applied Sciences, Amsterdam, the Netherlands

Aim & Methods

A recent survey under the Amsterdam University of Applied Sciences' first year fresh men learned that 16% of them were informal caregivers. About 8% spent more than 4 hours a week on care tasks.
A more elaborate research conducted by the Community Care Research Group among 800 students at the AUAS Faculty of Applied Social Sciences and Law, revealed that about two third of them could be looked upon as 'young carers' although only a quarter see themselves as such. Half of the young carers mentioned taking care of more than one person and four out of five reported performing more than one task. Reasons for giving care were diverse, as were the persons taking care of: in 40% respectively 49% of the cases care was given because of physical or psychiatric problems and parents were twice as much care recipients as siblings.
For those, the combination of study and taking care of a family member is their everyday reality with severe consequences for their personal life (mentioned by 73%) and their studies (63%). It is not surprising that only 44% of the 'caring students' never had to miss classes (opposed to 78% of those without care responsibilities) and 29% missed class two till four times the last two weeks.
It is clear that universities have to take measures to provide more support toward their caring students. The risk that the burden of caring tasks causes the students to experience delay in their studies or quit altogether is high. This causes an unwanted disruption of the desired life course. During open interviews students expressed their wishes about the support they wanted from their lecturers, mentors and the AUAS as a whole. In our presentation we want to elucidate our findings about how AUAS can contribute to the sense of belonging of its young carers. A sense of belonging indeed is not only a feeling or experience, but it also has to do with (a more practical) inclusive policy.

O – 90

Abrupt inclusion: People with disabilities in transitions, crises and change

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Aim & Methods

Belonging and inclusion happen when we and others believe we belong and see the demonstration that it is true. But what happens in times of transition, crises and change? This presentation brings together research related to the transformative inclusion of women, men, boys and girls with disabilities in situations of disasters, and crises propelled by resource extraction. I argue there are strategic moments when we can do more to promote transformative inclusion than at other times. Yet these moments have two faces – the possibilities of transformative inclusion, as well as of marginalization, exclusion and oppression.
Neutrality is not possible – we change in order to include, and we either reject that inclusion or passively accept the status quo or offer suggestions to tinker with it, which also perpetuates exclusion. At an individual and family level, these strategic moments are often times of life transitions – to childcare, from childcare to school, from school to work, from work to retirement. Just as life transitions offer opportunities for responses that illustrate belonging and inclusion, so too do times of transition and change following conflicts and natural or environmental disasters. In these cases, vulnerability is experienced more widely within societies, countries and across the world. I suggest that these transitions

after conflict or crises offer unusual opportunities to look for and claim transformative inclusion at community, national and international levels. We must rebuild after these events, but we have an opportunity to build back better and more inclusively.
Drawing on data from two large-scale research projects, this paper explores the theoretical and practical implications of and requirements for the abrupt inclusion or belonging that can arise in the context of natural disasters, environmental change and situations of crises as a result of resource extraction.

O – 91

Belonging, Meaning, and Identity: Living with Severe Traumatic Brain Injury

Douglas Kidd
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Aim & Methods

Summary: With his life trajectory profoundly altered by a catastrophic automobile accident, the physiological separation Douglas Kidd's brain experienced from time and reality for 65 days while in states of coma and amnesia produced complete social disconnection. This auto-ethnographical account examines how Douglas establishes his identity, derives meaning, discovers community, and finds belonging as he transitions from nondisabled to life with physical, cognitive, psychological, and emotional impairments. This paper explores temporal dissonance Douglas at times experiences as he processes, copes with, and manages his surroundings. These altered perceptions of reality and time occur as Douglas's brain is overwhelmed by sensory input, and then he decompensates. While seemingly detrimental, Douglas regards these episodes of altered perceptions of reality as necessary for his identity development and encourages him to recognize his life with impairments. During his recovery from the severe traumatic brain injury he acquired, Douglas found acceptance and forged community with other impaired individuals. These disabled communities provide him with opportunities for advocacy, vocation, and artistic expression by presenting to conferences, and composing essays, articles, and poetry. Douglas's life and connection to disabled individuals, as well as the larger disabled community, lead him to experience a profound sense of belonging.

O – 92

Belonging as important element of QoL in persons with PIMD: A qualitative study on physicians' perceptions

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Aim

Persons with Profound Intellectual and Multiple Disabilities (PIMD) are totally dependent on support from others for all aspects of their daily needs and cannot verbally express Quality of Life (QoL) themselves. This can be a burden for the persons who are responsible for them such as parents, care takers and physicians, especially in ethical decision -making processes on, for example, major surgery and tube feeding. According to literature QoL is often a key factor in decision making. However, how physicians perceive QoL in persons with PIMD has hardly been examined. The objective of this study was to explore how physicians describe good and poor Qol in persons with PIMD.

Method

We conducted semi-structured interviews with 3 pediatricians and 4 Intellectual Disability- physicians with more than 5 years of experience with the target group. The interviews were coded with a coding tree, which was developed through consensus between different researchers.

Results

Participants referred to several elements of QoL, which were clustered: an emotional cluster, bodily cluster and relational cluster. The latter included (the capability to make) contact with significant others. Good QoL meant that these clusters were positive, and poor QoL that they were negative. Also an equilibrium between elements, especially between the person with PIMD and their relational context, were seen as good QoL. However QoL, according to participants, tended to be poor when there was a negative change in the bodily elements, like decline or bad prognosis, or in the relational elements, like the decline of strength, decline of resources or death of parents.
Physicians frequently mentioned the dependency and therefore the necessity for persons with PIMD of a warm and loving environment.

Conclusions

The findings suggest that physicians do not only take elements of the person with PIMD into their considerations when they value QoL but also their relational context, suggesting that belonging to their relational context is an important element of (physicians' interpretations of) QoL.

O – 93

How are notions of wellbeing and belonging constructed in the accounts of autistic adults?

Damian Milton
London South Bank University, London, United Kingdom

Aim & Methods

This presentation will reflect upon a small-scale exploratory study which sought to develop an understanding of the meaning of well-being and social belonging as represented within the narratives of adults on the autism spectrum. Employing an interpretivist approach facilitated the investigation of potential contributory factors to these lived experiences in order to inform further research regarding both this topic, and service provision for adults on the autism spectrum. The project involved a thematic analysis of issues of the magazine Asperger United (AU). Four broad main themes were identified: meeting personal needs, living with the consequences of an 'othered' identity, connection and recognition, and relationships and advocacy.

Results & Conclusions

Autistic adults reported many barriers to feeling that they belonged in a number of social spaces and the detrimental effect this had on their wellbeing. Fundamental to positive narratives of wellbeing, were feelings of connection and recognition from others and positive accepting relationships, with autistic-led spaces, particularly the Autscape conference, being frequently cited as of central significance in increasing feelings of wellbeing and belonging. This study has demonstrated a need for less focus on remediation and more on limiting the social isolation of autistic people.

O – 94

'Belonging' as starting point to understand QoL of persons with PIMD. A narrative identity approach

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Aim

Persons with Profound Intellectual and Multiple Disabilities (PIMD) cannot speak about their own Quality of Life (QoL), which limits the reliability and validity of the current instruments used to assess their QoL. More importantly, the current approaches do not recognize the multiple ways in which persons with PIMD belong to the stories others tell about them. The objective of this study is to highlight the relational dimensions of a narrative identity approach to QoL of persons with PIMD.

Method

Based on our recent literature review study on QoL of persons with PIMD, some of the shortcomings of the current approaches to QoL of persons with PIMD will be described. Narrative theories will be used to develop a narrative identity approach to QoL of persons with PIMD.

Results

Based on common sense interpretations of the good life, researchers have developed standardized domains, indicators and items to determine QoL of persons with PIMD. However, by focusing on the commonalities and generalizations, these approaches have ignored the fact that QoL is someone's QoL. Therefore we should ask proxies to tell stories about them. In that case, proxies are no longer reduced to (distanced or close) observers, like they are in the current approaches to QoL. For example, a father may tell a different story than a friend. Stated differently, the particularities of their relationships with the person with PIMD may highlight similar and different perspectives on the person with PIMD and her/his QoL. In addition, a narrative identity approach acknowledges that these proxies all have their own histories with the person with PIMD. This history colours their relationship and their interpretation of QoL.

Conclusions

The variety of relationships of persons with PIMD is reflected in the stories others tell about them, which is not weakening but strengthening the interpretations of QoL. Future studies should explore how the particularities of these stories and relationships offer unique understandings of QoL. In addition, future research should examine how these stories are told when conflict arises on the interpretation of QoL.

O – 95

The art of living and belonging in severely complicated situations Toward an understanding of the experiences of “challenging behaviour” in long-term care

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Aim

This contribution is about very vulnerable people who have permanent disabilities. They are dependent on long-term care and threatened to end up in complicated situations in which the quality of life is severely under pressure. Their behaviour is experienced as very challenging by the private and professional caregivers around them. This carries in it the risk of exclusion. Caregivers may start to avoid the person, relationships may become so complicated that they are no longer caring, healthcare institutions may decide to transfer the person, and so on. What does the art of living and belonging mean when it comes to these people whose lives have become so difficult?

Methods

This contribution is based on qualitative research into the experiences of the people involved. This research consists of various sub-studies and is work-in- progress.

Results

This contribution shows that the art of living and belonging in such severe situations requires caregivers who shift their focus from “people with challenging behaviour” to “people involved in challenging situations”.

Conclusions

When caregivers manage to think and act accordingly, they practice an art of belonging rather than exclusion. The “Centrum voor Consultatie en Expertise” (www.cce.nl) can be consulted by caregivers involved in challenging situations with clients with permanent disabilities who require long-term care and support. It is always about very complex situations in which the quality of life of people is seriously under pressure. Through qualitative research connected to this consulting practice, more insight is gained into the perceptions, meanings, interests and values of the people involved in these challenging situations.

O – 96

The art of conversation: finding new ways to talk with Siska

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Aim & Methods

People with complex communication needs make wonderful teachers for those of us who interact in highly conventional ways. This presentation will take the form of an interactive workshop illustrating how we all learned to have different kinds of conversation with Siska, a 37 year old lady who lives in a group home. Siska is the youngest of three sisters. She has severe intellectual disabilities with no specific diagnosis. Her receptive vocabulary (Peabody Picture Vocabulary Test) has been assessed as equivalent to 2;6 years, and her receptive language overall (Reynell Developmental Language Scales) as 2;9. We started the exploration of her communication in 2013. At that time, she expressed herself in short phrases which appeared quite stereotyped, and conversations with her often got stuck in repetitive loops. Staff were not sure how support her to change what felt like very ingrained patterns of behaviour. We therefore began a process of enquiry, observing closely what was happening in these conversations through video analysis and discussion. Over the years, we have created an informal team consisting of Siska herself at the centre, Siska's family members, the staff who support her, associated professionals and an independent adviser specialising in narrative and early communication. Through close co-operation and led by Sitka's interests and responses, we have developed some different ways of talking together which allow Siska to show us aspects of her personality and her communication skills – her sense of humour, her interest in others, her awareness of major life events and her memories. In this demonstration we will tell the story of how we problem solved together, viewing Siska's communication rather like a poem or work of art that is profoundly significant and challenging and where multiple interpretations are possible. We will illustrate our process by examples which participants will be invited to explore by discussing the questions that arise, and how they could be approached. We will share some of the strategies that we found effective in enabling us all to have conversations that feel enjoyable and meaningful.

NL

De kunst van het gesprek: nieuwe wegen zoeken om te praten met Siska

Mensen die moeilijk praten zijn goede leraars voor goede praters. In deze workshop ontdekken we hoe het gesprek met de 37-jarige Siska op verschillende manieren kan plaatsvinden. Siska heeft een ernstige verstandelijke beperking. Sinds 2013 onderzoeken we haar taal en haar mogelijkheden tot dialoog voeren. In 2013 sprak Siska met korte eenvoudige zinnetjes die steeds terugkwamen. De voorbije jaren is er intensief gewerkt met Siska en met haar familie, vrienden en ondersteuners. Door deze nauwe samenwerking zijn er nieuwe vormen van gesprek ontstaan. We hebben beter zicht gekregen op haar persoonlijkheid, haar taalvaardigheden, haar gevoel voor humor, haar interesse in anderen, haar bewustzijn van belangrijke mijlpalen in het leven en op haar herinneringen. In deze workshop demonstreren vertellen we dit verhaal. We kijken naar Siska's taal als een vorm van kunstwerk, als een gedicht. Zoals kunst belangrijk is, en altijd meerdere betekenissen heeft, zo is ook Siska's taal. We zullen inzicht geven in onze zoektocht naar wat hielp om gesprekken te voeren die fijn en betekenisvol waren.

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Mechanisms and influencing factors in strengthening social networks of persons with disabilities

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Aim

The purpose of this research project is mapping the complexity and dynamics of the social network around a person with a disability from different point of views (persons with disabilities, network members and his/her professional in an ambulatory home-based service), as well as the influencing mechanisms and factors for network development and support. This research is embedded in an academic workplace where researchers and teachers (University of Leuven; Higher education UCLL), professionals, persons with disabilities and their network work closely together on the research design, data-analysis, results and translation of results into daily practice.

Methods

The research project is constructed of 14 case-studies, each consisting of a semi-structured interview with a person with a disability, two of his/her network members and his/her professional in an ambulatory home-based service. Interview topics mainly focused on: structural and functional characteristics of the social network around a person with a disability, satisfaction with the social network; material, physical and psychological wellbeing of the person with a disability; social participation of the client; expectations towards the professional; needs and wishes of persons with disabilities and network members. The interviews were transcribed and coded in NVivo.

Results

Factors and mechanisms that were identified as influencing the social network of a person with a disability are: reciprocity, degree of contact, number of persons in the social network, understanding, respect, appreciation, accessibility, trust and the quality of the tie with the other persons in the social network.

Conclusions

The identified mechanisms and influencing factors will be concentrated in a conceptual model, which will be empirically validated in the next research stage.

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Arts Therapies in community based treatment teams for people with mild intellectual disabilities

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Aim & Methods

In the Netherlands, more and more initiatives are being taken to support people with mild intellectual disabilities (MID) in the community instead of in institutions. The care offered by these community based treatment teams could benefit from non-verbal, experiential methodologies, because people with MID struggle to process information that is communicated verbally. The non-verbal, experiential perspective is seen in arts therapies (AT). AT is a widely used therapy in institutions for people with MID and consist of music therapy, art therapy, drama therapy and dance-movement therapy.

Research has shown positive effects among persons with MID and behavioral problems. However, at this moment AT are not included in organizational models for community based treatment. The aim of this research was to develop a treatment route for AT within community based treatment teams, like FACT-teams. This route provides a structure for why, when and where AT can be of value.

First, four focus groups have been conducted in order to determine the added value of AT for patients with MID. These focus group interviews contained 22 arts therapists from four clinical institutions.

Second, seven interviews were conducted with FACT-team professionals in order to focus on opportunities for collaboration between FACT-teams and arts therapist. The results of the focus groups and interviews were translated towards a route, that provides a work structure for the collaboration of arts therapies with community based treatment teams. This route is implemented in two FACT-teams and the implementation process and the first experiences with the route were evaluated.

Descriptive analysis are conducted at the moment. But the first results seems to indicate that arts therapists can successfully collaborate with FACT-teams for people with MID, when conditions, like insight in each other's role, treatment possibilities, language, etc. will be arranged.

The perspective and expertise of arts therapists is of added value when drawing up a treatment goal and plan and in treating persons with MID.

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Participatory quality improvement of complex relationships in care for people with learning disabilities

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Aim & Methods

The relationship between people with learning disabilities and their professional carers becomes increasingly complex as providers have the both enhance user participation and care for vulnerable clients. Insight into this complexity is important in long term care since the quality of this relationship does not only impact the experienced quality of care but also the quality of life. To gain an in-depth understanding of this relationship and to employ these insights for quality improvement qualitative methods for collecting experiences and deliberative methods for reflection on dilemma's in the care relationship are important. From experience with qualitative improvement methods and deliberative methods, we know that in general they are considered highly useful by clients and professionals alike. It is also known however that translating the findings to actual quality improvement often does not happen. In response to this problem, methods have been developed which specifically focus on translating the stories of clients (and family members) and health care professionals to quality improvement. Experience Based Co-Design (EBCD) is an inspiring example of such a method in which providers, service users and family co-design quality improvements. In the current study, we use participatory action research in order to adjust Experienced Based Co-Design process to enable people with mental disabilities to participate in quality improvement of care. In this paper we present our preliminary findings.

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