

Sharing experiences with inclusive approaches in health research and teaching about ID in academic curricula

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30 July 2026



University College Dublin
An Coláiste Ollscoile,
Baile Átha Cliath





Priority pile



Active involvement of people with ID in research – sharing experiences

Stacey de Jong-Witjes, PhD candidate (presenter)

Judith Thoonen, co-researcher

Our study

Stakeholders' viewpoints on the concept of health for people with an intellectual disability, a qualitative and inclusive study



Academic collaborative Intellectual disability and Health –
Sterker op Eigen Benen (SOEB), Nijmegen, The Netherlands.

SAMEN ONDERZOEKEN

Focusgroeponderzoek met co-onderzoeker

Stacey de Jong-Witjes en Judith Thoonen



Stacey en Judith schrijven ook samen blogs voor www.gezondsterker.nl
Wil je meer lezen over hun ervaringen? Scan de QR code!

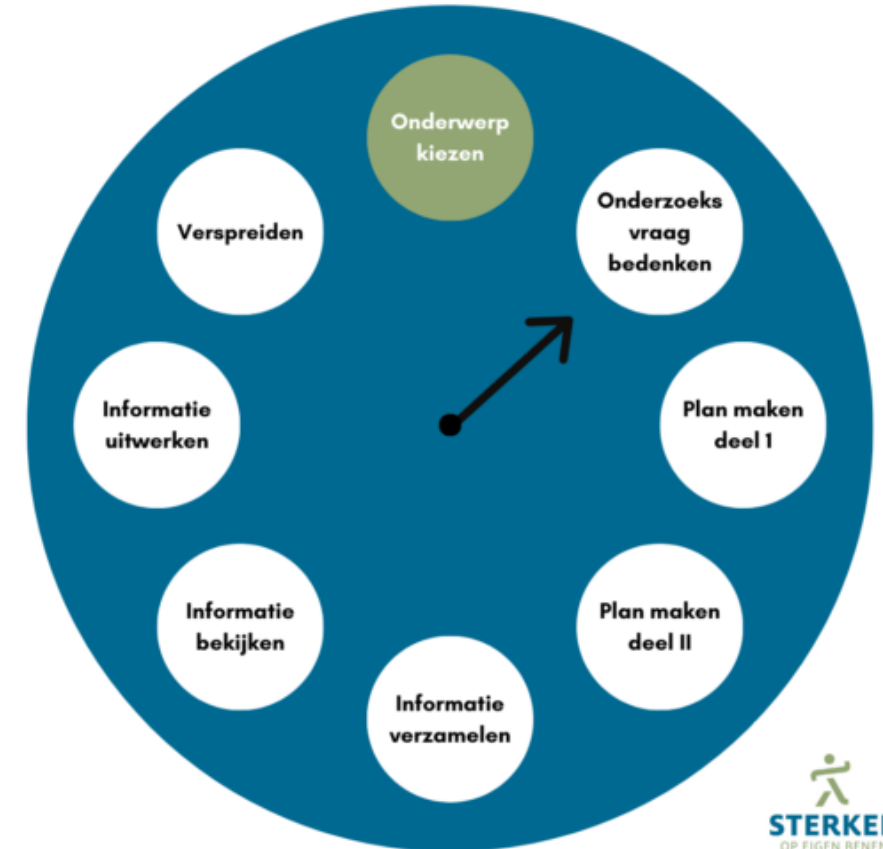
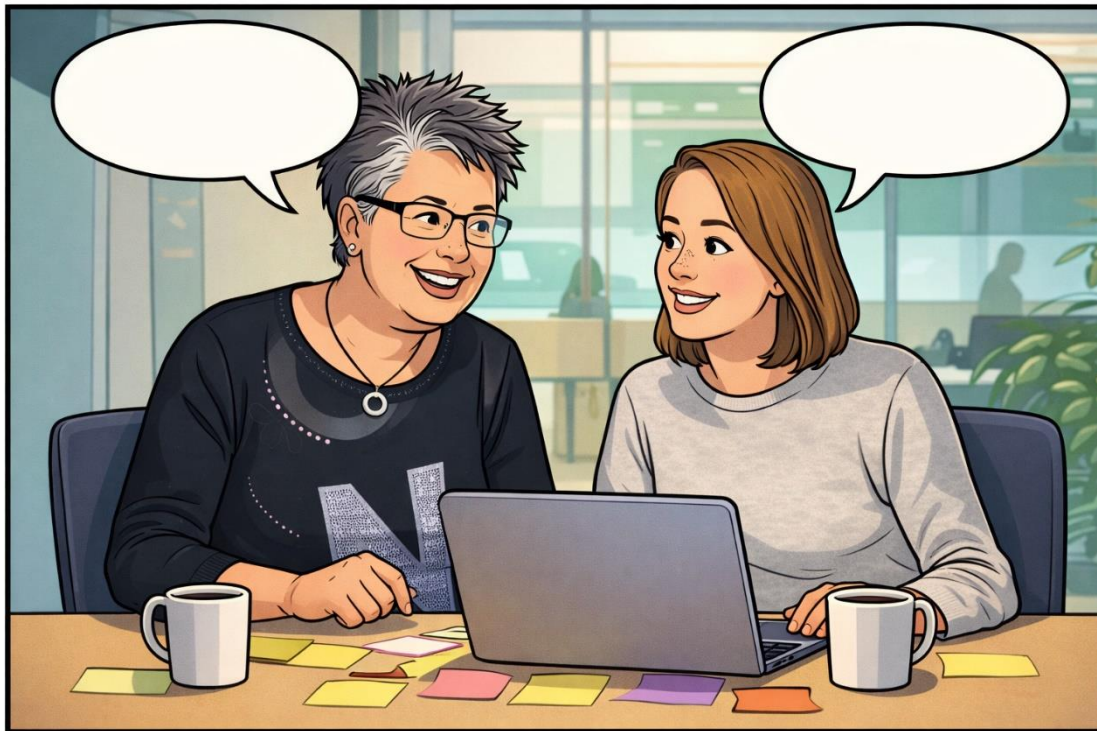


Meet the team



Preparing ourselves

Preparation is essential!



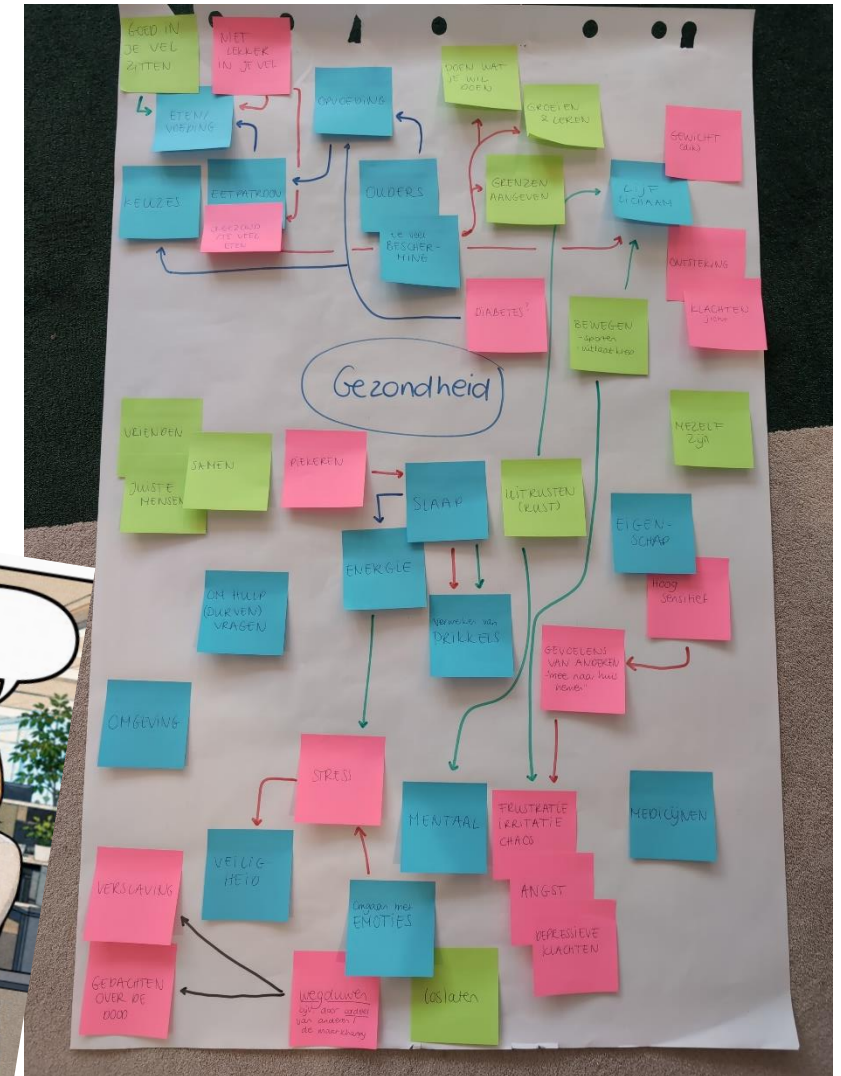
Practice



Practice makes perfect!

Analysis

Thematic analysis: identifying **key patterns** and **meanings**



Take home message

Our most important take home message – from Judith herself!



Thank you for your attention!





Inclusive Education & Experts by experience as lecturers

Fleur Heleen Boot, MD, PhD
Radboudumc, Intellectual Disability Medicine

What do we do?



What do we do?



How did we get there?

- The implementation of our inclusive education programme was made possible through:
 - visionary leadership
 - persistent networking
 - engaging clinical champions
 - dedicated funding
 - interdisciplinary collaboration
 - the meaningful involvement of experts by experience as equal educational partners.

What are current challenges?

- Keep advocating for staying in the curriculum
- It feels like you are depended on passionate others for keeping this education, e.g. general practitioners with a coordinating role in the curriculum.
- Strong education role within your department is needed for the lecturer who provides and organises these lectures.
 - The lecturer is committed to continuous professional development and to further strengthening her role as an educator.

Ethical Dilemmas

Inclusive teaching of intellectual disability for healthcare professionals

Christine Linehan



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Many reviews exploring programmes for healthcare professionals



RESEARCH

Open Access

Intellectual disabilities teaching for medical students: a scoping review

Georgia Towson¹, Stephanie Daley^{1*} and Sube Banerjee²



Educating the educated: The impact of educational interventions on knowledge, attitudes and confidence of healthcare professionals in caring for patients with intellectual disability: A systematic review

Gracie Hay, Nathan J. Wilson, Natalie Ong, Patrick Benson & Gisselle Gallego

REVIEW

JARID WILEY

Health professionals' education related to people with intellectual and developmental disabilities: A scoping review

Sarah H. Ailey¹ | Molly Bathje² | Renáta Tichá³ | Brian Abery³ | Belle K. Khuu³ | Lisa Angel¹

Health professional education in autism and intellectual disability: systematic review

Catherine Franklin, Sinead Green, Katie Brooker, Ruby de Greef, Carla Meurk and Edward Heffernan

RESEARCH ARTICLE

Open Access

Has teaching about intellectual disability healthcare in Australian medical schools improved? A 20-year comparison of curricula audits

Julian N. Trollor^{1*}, Claire Eagleson¹, Beth Ruffell¹, Jane Tracy^{2,3}, Jennifer J. Torr⁴, Seeta Durvasula⁵, Teresa Iacono⁶, Rachael C. Cvejic¹ and Nicholas Lennox⁷



Academic Psychiatry (2021) 45:371–381
<https://doi.org/10.1007/s40596-020-01378-8>

SYSTEMATIC AND OTHER REVIEW

Post-graduate Medical Training in Intellectual and Developmental Disabilities: a Systematic Review

Zachary Adirim¹ | Sanjeev Sockalingam² | Anupam Thakur²

RESEARCH

Open Access

Intellectual disabilities teaching for medical students: a scoping review

Georgia Towson¹, Stephanie Daley^{1*} and Sube Banerjee²



REVIEW

JARID WILEY

How are medical students learning to care for patients with intellectual disabilities? A scoping review

Hana Anderson^{1,2} | Amy C. Studer³

Some issues to consider from reviews in this field



Very little data on meaningful inclusion of individuals with intellectual disability

Inclusion of self advocates is primary instructional approach

Low but growing proportion of co-design or co-delivery

Use of recorded patient narratives from the lived experience of people with intellectual disabilities and their families

Immersive, experiential learning included visiting homes (in one case not advised of the specific disability before visiting to avoid pre-assumptions)

No articles discussing how programming was influenced by or related to intersectionality.

Considerable reporting of programme evaluations being of low quality

It is a stark weakness that evaluation ...relies on the perceptions of those students/practicing professionals.

Minority of studies were rated high quality.

Majority of studies used unpublished and unvalidated bespoke measures.

Majority of studies for professionals were conducted as single session training programs.

Majority of programmes were elective with a bias toward interested students and message that content is optional.

Some issues to consider from reviews in this field



Outcomes for healthcare professionals targets knowledge not behaviour change

Programmes typically classified by Kirkpatrick Level 2 (change in knowledge) rarely as Level 3 (**change in behaviour**)

High level education outcomes such as **behavioral changes were not observed** consistently in the studies reviewed.

Inconsistent use of competencies for training in published curricula despite their availability

Outcomes for individuals with intellectual disability are rarely examined

Evaluations of outcomes for people with intellectual and developmental disabilities were rarely presented.

This type of data requires a **long duration of data collection** yet -

Majority of programmes collect evaluation data **immediate on cessation**.

Few studies explore **persisting effects** (e.g. one to two year follow up)

Talking points

Very little data on experiences of people with intellectual disability participating in educational programmes – is inclusion meaningful?

Considerable reporting of low quality evaluations using non-validated measures.

Impact on healthcare professionals is largely assessed in terms of changing knowledge rather than changing behaviour.

Very little evidence of direct impact educational programmes have on health outcomes for people with intellectual disability



The quest for inclusive research in academic settings: challenges

Jenneken Naaldenberg, PhD

Inclusive research what we do

-  Working with inclusive research for over 10 years
-  A team of four co-researchers
-  Supported by a dedicated project group with a coordinator and researchers
-  Collaboration in long term research projects as well as advisory work on study basis
-  Continuous reflection on impact of inclusive research
-  Lead by example in open science

Inclusive research how did we get here

-  Important first step was decision to have co-researchers as employees and part of the research group
 -  This increased awareness and visibility among the research group and within the research department
 -  Dedicated coordinator facilitates both researchers and co-researchers with practical support like organizing transport, developing job descriptions, collaboration with other inclusive research groups
- Willingness to learn from both co-researchers and researchers

Inclusive research challenges

-  Inclusive research deviates from many/most academic routines
-  Academic environments not very accessible
-  Proper payment difficult to achieve
-  Share and safeguard experiences, tools and materials
-  Visibility of impact

A close-up photograph of a stack of books. The top book has a yellow cover, the middle one has a teal cover, and the bottom one has a light blue cover. The spines of the books are visible, showing the texture of the paper and the binding.

Revisit the priority pile

The background of the slide features several paper cutouts of human heads in profile, arranged in a cluster. Some heads are white with a large black question mark inside, while others are light blue. One head in the center is white and contains a blue line drawing of a lit lightbulb. A bright pink rectangular box is overlaid on the left side of the image, containing the text 'Discussion of top priorities' in white.

Discussion of top priorities