

Equality and Inclusivity within rehabilitation medicine: new roles and challenges



Sander R. Hilberink, PhD
Research Center Innovations in Care
Rotterdam University of Applied Sciences



**Research Centre
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Disclosure of speaker's interests

Sander Hilberink

(Potential) conflict of interest	None
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<ul style="list-style-type: none">▪ Sponsorship or research funding▪ Fee or other (financial) payment▪ Shareholder▪ Other relationship, i.e. ...	

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Camp Jened: Crip Camp (Netflix)



NETFLIX

OFFICIAL
TRAILER

Camp Jened: The birth of the...

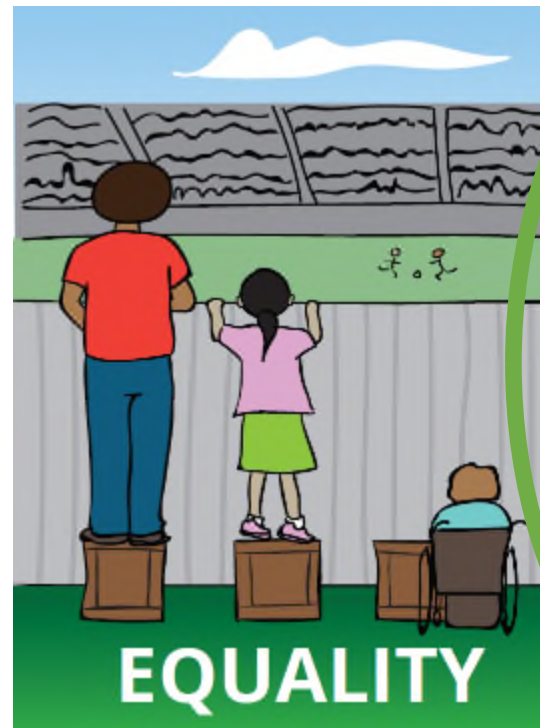


- Adopted in 2006 by the UN, ratified by the Netherlands in 2016
- Extensive lobbying by many organizations
- Ensures:
 - Access to ‘a normal life’
 - Including Healthcare and Support Services

“Rehabilitation for all: *equality* and inclusivity”

Key-terms:

What is Equality?



“Rehabilitation for all: equity and *inclusivity*”

Key-terms:

What is *Inclusivity*?

Still normative?

“Rehabilitation for all: equity and *inclusivity*”

Key-terms:

What is *Inclusivity*? *"We want to move towards a society where everyone can feel free. I also prefer to talk about expansion rather than inclusion. With inclusion, groups often have to fight their way into the existing society, but with expansion, society itself changes. Society creates space for underrepresented and marginalised groups."*

Key-terms revisited

“Rehabilitation for all: equity and expansion”



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Citizenship: A broad definition

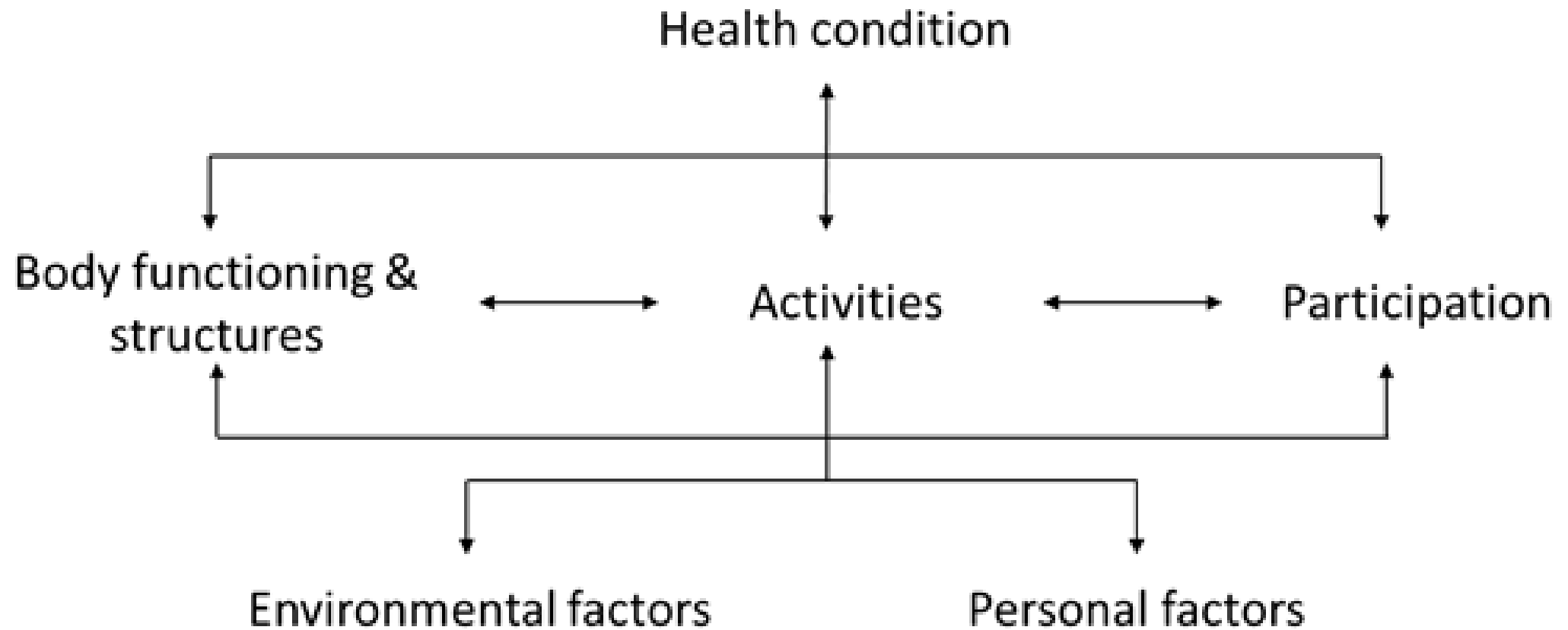
“A person being integral to their community, a person who both is valued and respected, and feels valued and respected within their community; a person whose inherent dignity as a human being is upheld; and a person whose uniqueness is not only recognized but is also considered a valuable contribution to a rich and dynamic societal fabric.”



Citizenship: A broad definition

- Today, I will discuss three themes how Rehabilitation Medicine can further contribute to citizenship
 - Intimate relationships and Sexuality
 - Preventive Medicine and Perinatal care
 - Longterm care

Intermezzo: The ICF



Citizenship d950

Participation and Personal Factors

Intimate relationships and sexuality (1)

- Having a physical disability and its severity are related to being single
- Men with physical disabilities are more likely than women with physical disabilities to be single
- Women with physical disabilities have the same sexual needs and desires as women without disability, but their body image, sexual self-esteem and sexual satisfaction are significantly lower

Namatovu, F., Häggström Lundevaller, E., & Vikström, L. (2020). The impact of disability on partnership formation in Sweden during 1990-2009. *The History of the Family*, 25, 230-245. <https://doi.org/10.1080/1081602X.2019.1692054>.

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Intimate relationships and sexuality (2)

Body Functions and Structures

- Incontinence
- Erectile and lubrication problems
- Positioning
- ...

Environmental factors

- Taboo in rehabilitation
- Many centers lack policy
- Inaccessibility of sexual services

D'Andrea, S., Castellini, C., Paladino, V., Totaro, M., Felzani, G., Francavilla, S., Francavilla, F., & Barbonetti, A. (2020). Metabolic syndrome is the key determinant of impaired vaginal lubrication in women with chronic spinal cord injury. *Journal of Endocrinological Investigation*, 43(7), 1001–1007. <https://doi.org/10.1007/s40618-020-01185-w>.

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Activities and Participation

Intimate relationships and sexuality (3)

- Solo-sex
- Partnering
- Kissing
- Communication
- ...



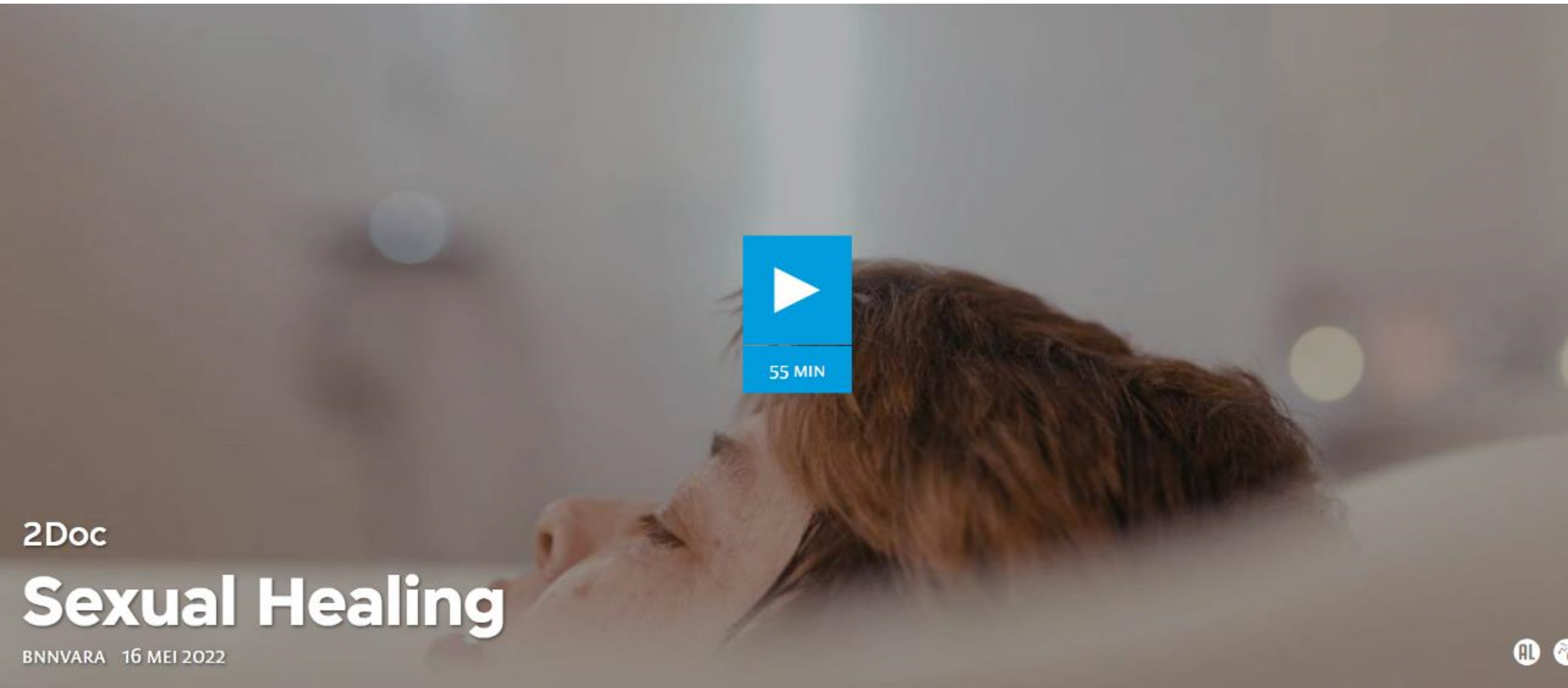
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2Doc

Sexual Healing

BNNVARA 16 MEI 2022

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55 MIN

Sexual Healing

<https://www.2doc.nl/documentaires/2022/05/sexual-healing.html>

Implications for rehabilitation

- Support marital quality and sexual health (policy)
- Addressing sexuality is a team effort (physician, nurse, occupational therapist, physiotherapist, speech therapist, sexologist, ...)
- Advocate for better access to sexual services

Welten, J.J.E., Cox, V.C.M., van Eijk, R.P.A., van Heugten, C.M., Visser-Meily, J.M.A., & Schepers, V.P.M. (2023). The Effects of a Blended Care Intervention in Partners of Patients With Acquired Brain Injury - Results of the CARE4Carer Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation*, S0003-9993(23)00517-8. Advance online publication. <https://doi.org/10.1016/j.apmr.2023.08.024>.

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Environmental factors

Access to preventive medicine

- Access to routine check-ups affects all preventive services independent of disability level
- Young adults with disabilities report more unmet health needs
- Women with disabilities receive fewer cervical screening and clinical breast examinations

Diab, M.E., & Johnston, M.V. (2004). Relationships between level of disability and receipt of preventive health services. *Archives of Physical Medicine and Rehabilitation*, 85(5), 749-757. <https://doi.org/10.1016/j.apmr.2003.06.028>.

Callahan, S.T., & Cooper, W.O. (2006). Access to health care for young adults with disabling chronic conditions. *Archives of Pediatrics & Adolescent Medicine*, 160(2), 178-182. <https://doi.org/10.1001/archpedi.160.2.178>.

Pharr, J.R., & Bungum, T. (2012). Health disparities experienced by people with disabilities in the United States: a Behavioral Risk Factor Surveillance System study. *Global Journal of Health Science*, 4(6), 99. <https://doi.org/10.5539/gjhs.v4n6p99>.

“My first mammogram was a disaster, mainly due to the attitude of one of the professionals involved. (...) The radiologist was just obnoxious in many ways but the final straw was when she shouted that my PA [personal assistant] must remain in the waiting room. I tried to explain and she shouted again. I became tearful so left. When calm, I talked to a receptionist in a different part of the building who offered to go back with me to ask they talk with me respectfully. Mrs Obnoxious announced she had already written to her boss in case I complained!”

Body Functions and Structures

Pregnancy and disabilities (1)

- Poorer preconception physical health
- Urinary tract and bladder problems
- Shortness of breath
- Increase of spasticity
- Bowel management difficulties
- Stability problems and falls

Environmental factors

- Wheelchair fit reduces mobility and compromise safety
- Wheelchair and home adaptations for newborn

lezzoni, L.I., Wint, A.J., Smeltzer, S.C., & Ecker, J.L. (2015). Effects of disability on pregnancy experiences among women with impaired mobility. *Acta Obstetrica et Gynecologica Scandinavica*, 94(2), 133–140. <https://doi.org/10.1111/aogs.12544>.

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Pregnancy and disabilities (2)

- Lack of support from healthcare providers
- Difficulty transferring onto fixed-height examination tables
- Being examined while sitting in their wheelchairs
- Not being routinely weighed on an accessible weight scale by their prenatal care clinicians

Iezzoni, L.I., Wint, A.J., Smeltzer, S.C., & Ecker, J.L. (2015). Physical Accessibility of Routine Prenatal Care for Women with Mobility Disability. *Journal of women's health* (2002), 24(12), 1006–1012. <https://doi.org/10.1089/jwh.2015.5385>.

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Body Functions and Structures

Pregnancy outcomes and disability

- More often pre-term births
- More often low birth weight babies

- Women with orthopedic conditions
 - Less often spontaneous birth
 - More often planned Cesarean birth
 - More often emergency Cesarean birth



Webinar

Providing Perinatal Care to Expectant Mothers with Physical Disabilities

Monday, May 25
Noon ET
via Zoom

Use the QR code to register



Mitra, M., Clements, K.M., Zhang, J., Iezzoni, L.I., Smeltzer, S.C., & Long-Bellil, L.M. (2015). Maternal Characteristics, Pregnancy Complications, and Adverse Birth Outcomes Among Women With Disabilities. *Medical Care*, 53(12), 1027–1032. <https://doi.org/10.1097/MLR.0000000000000427>.

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Implications for rehabilitation

- Advocate for accessible preventive measures
- Cooperation with and education of perinatal professionals
- Pro-actively inform women with disabilities and timely help to make arrangements (to train skills and organize adaptations/support)

van der Vliet-Torij, H.W.H., van Heijningen-Tousain, H.J., van Heijningen, V.G., Schildmeijer-Ruesink, M.C., Folkertsma, T. W., Rosman, A.N., & Hilberink, S.R. (2023). Equipping future professionals in supporting pregnancy, childbirth, and parenthood with a physical disability. *European Journal of Midwifery*, 7(Supplement 1).

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Environmental factors

Access to longterm care

- The decentralization of longterm care results in fragmentation
- 25% of persons with disabilities have been confronted with extra barriers with regard to access to personal care and support services
- Adequate support is in some cases withheld
- Application procedures are cumbersome and sometimes redundant
- Re-applying for care and support is stressful and hampers continuity

Bredewold, F., Duyvendak, J.W., Kampen, T., Tonkens, E., & Verplanke, L. (2018). De verhuizing van de verzorgingsstaat. Amsterdam: Uitgeverij van Genneep.
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Access to longterm care



Netwerk voor mensen met een
beperking of chronische ziekte

Take home messages

- Expansion
 - Bring rehabilitation to other medical professions to improve the quality of care, including perinatal care and preventive medicine
 - Implement policies for sexual health (in couples and access to sexual services)
 - Get involved in the public debate on accessible society and longterm care



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Questions

