

Dissemination and utilization of disability data

putting implementation of the UN convention on the rights of persons with disabilities on the agenda

New York 2017 Steen Bengtsson





The UN convention on the rights of persons with disabilities (UNCRPD)

- **UNCRDP** was ratified by the Danish government in 2009
- And the additional protocol was ratified in 2014
- The government's point of view has been that UNCRPD did not demand any change in legislation
- The government formulated (2013) a disability policy Furthermore, a data and statistics overview was made Now (2017) an anti-discrimination law is proposed



As consequence of the ratification of UNCRPD: a breakthrough for disability statistics a

- Traditionally we have made much less disability research in Denmark than they have in neighbouring countries
- A breakthrough in the latest decade, in relation to the ratification of the UNCRDP

Two reasons for this breakthrough:

- 1. UNCRDP § 31 that demands statistics gathered and research made on disability
- 2. The establishment of a "watchdog" for the convention, the Danish Instute of Human Rights



UNCRPD § 31

The documentation project: registration on person of

- **1.** Use of sheltered housing for persons with intellectual disabilities and for persons with mental health problems
- 2. Use of support person for the same groups
- 3. Use of sheltered employment for the same groups (mostly persons with intellectual disabilities)

(status: 50% of the municipalities covered)

Establishment of an analysis office in the social department



UNCRPD § 31

- SHILD (Survey of Health, Impairment and Living conditions in Denmark)
- Survey of 20.000 persons, 16-64 years, in Denmark
- Carried out first in 2012, then in 2016 and planned for every fourth year: 2020, 2024, ... as a panel
- **Resulting in a report for each wave**
- And used for secondary analyses currently
- Earlier surveys (8.000 answers): 1961, 1995, 2006
- but SHILD is the first longitudinal survey



Content of SHILD 2016

- Definition: WG6, functional abilities, subjective disability, GALI
- Questions on personality, health, health behaviour
- **Education and employment**
- Family: parents, children with disabilities, partner
- Participation in near, informal and formal settings
- **Income and consumption of health products**
- Violence and discrimination against respondent
- **Use of public services**



The importance of a "watchdog" for implementation of the convention

- While the government is using more research, it also tries to influence the results it brings more than earlier
- This phenomenon is seen in all the fields that threaten to give a government expenses, such as environment, social conditions, etc.
- An independent watchdog can better resist the pressure from the government than a research institute



The Gold Indicators: by the Danish Institute of Human Rights and the Social Research Institute

https://www.humanrights.dk/activities/our-work-denmark/disability/gold-indicators-crpd

Purpose of the Gold Indicators

- **Development of the Gold Indicators**
- Indicators that were selected
- **Reflection of reality not legislation**
- The difference principle
- **Dissemination strategy**
- **Main results**



Purpose of the Gold Indicators

- Simplicity: just give a few numbers, not all the details that would be needed if it should cover the convention in its totality
- Overview: select the most central and important points from the convention to describe the conditions of people with disabilities
- Development: the instrument shall not only describe the essential points now, but also characterise the development that takes place over time



Development of the Gold Indicators

The method was selected so as to create

- 1. Ownership of the disability organisations and the state and municipal administrations by involving them into the process
- 2. Utilisation of the experience of researchers on people with disabilities by taking their advice in
- 3. Official status by involving the "watchdog", the Institute of Human Rights



Development of the Gold Indicators

The process:

Meetings with the parties (ca. 20 persons)

Selection of the most central points

Preparation to find candidates to indicators

Meeting for each indicator

Finding main indicator and three sub indicators



The ten indicators that were selected

Experience being discriminated against (discrimination, §5) Disabled people appear in the press (awareness, §8) Possible to use public transportation (accessibility, $\S9$) Risk of being imprisoned (freedom, \S 14) Experience having influence on own life (independence, § 19) Early school leavers (education, \S 24) Being at good health (health, § 25) Employed (employment, § 27) Experience deprivation (social security, § 28) Have voted in national elections (political participation, § 29)



Reflection of reality not legislation

e.g. not right to vote, but percentage that voted

e.g. not right to disability pension, but percentage who actually suffers deprivation

e.g. not schemes for employment, but percentage who actually was in work

etc., persons health, early school leavers, ...



The difference principle

- The indicators represent the difference between the situation for people with disabilities and others
- E.g. percentage with disability that voted, minus percentage without disability that voted
- E.g. percentage with disability who actually suffers deprivation minus percentage without disability who actually suffers deprivation

and so on



Dissemination strategy

Publication just before municipal elections

A disability barometer on the internet Kept simple as a point of departure, details below

A report (30-40 pages) describing the results more detailed



Main results

Generally the results for disabled people are significantly below results for others – excemption: political participation: (pwd vote more often than others)

Most marked:

deprivation, health, influence on own life

Development 2012-2016:

Seems to be in negative direction on most indicators, but not enough to give significant results