AFTER NORMALISATION – SERVICE DEVELOPMENTS IN SCANDINAVIAN COUNTRIES

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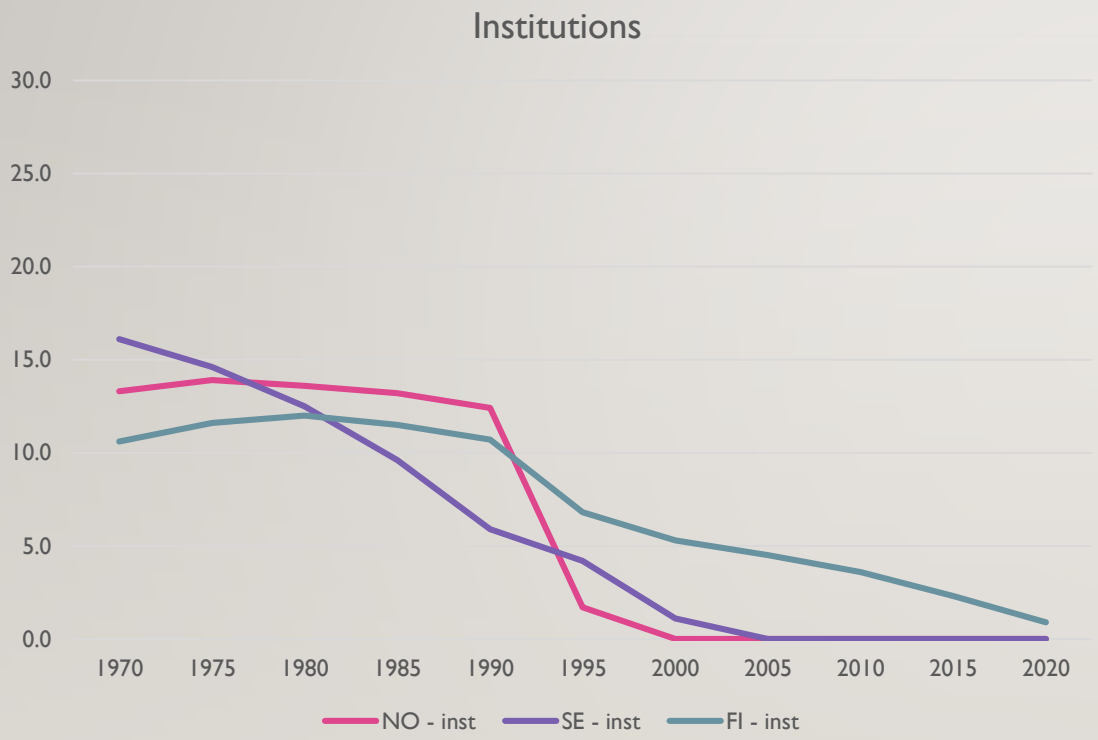
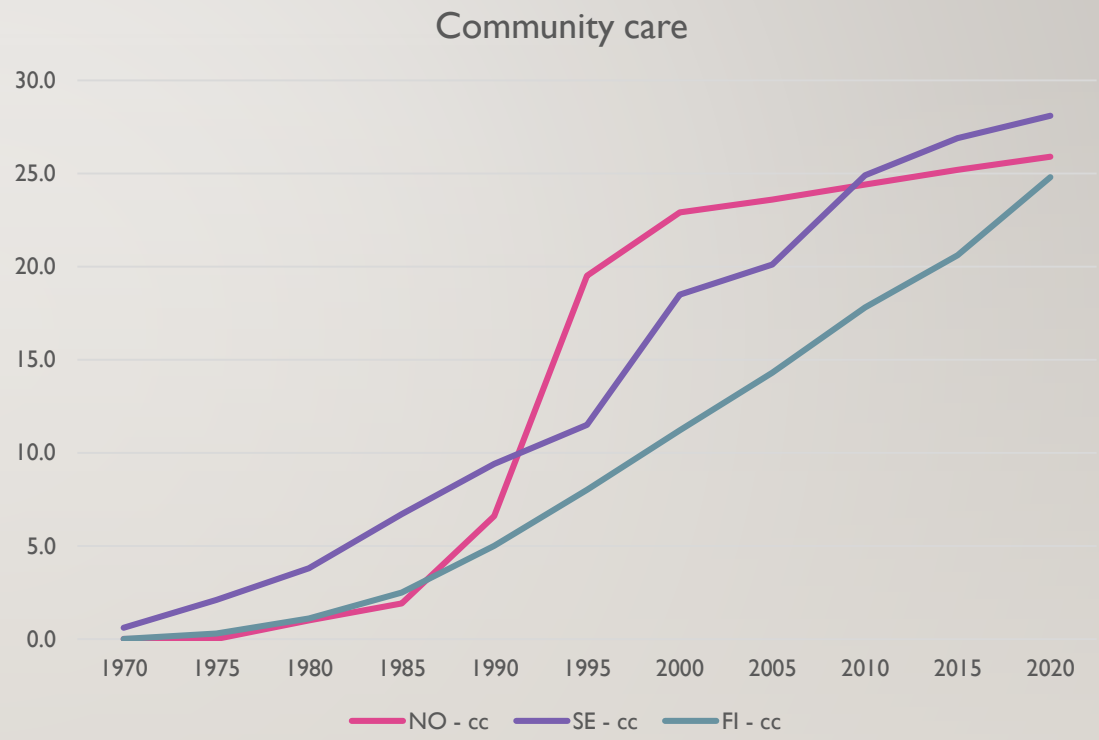
RELOCATION FROM INSTITUTIONS

- First countries to close all institutions for people with intellectual disabilities
  - In the 1990s
- Decided/enacted by national governments/parliaments
- Transfer of responsibility for services from the regional health administration to local authorities (generic services)
- Varying pace between Scandinavian countries
  - Sweden gradual from 1970-2003
  - Norway swift from 1990-1996
  - Other Scandinavian countries: Gradual from 1990, not yet finalised
- More people receive services

PEOPLE IN INSTITUTIONS AND COMMUNITY CARE PER 10 THOUSAND. NORWAY, SWEDEN, FINLAND





BACKGROUND – IDEOLOGICAL CHANGES

- The developmental model: becoming the subject
- Social justice and the welfare state: becoming a citizen
- Integration: a preference for generic services, "separate is not equal"
- The concept of normalisation as umbrella term, with a developing content
  - Preference for generic services (Sweden)
  - Lead a life as close to normal as possible (Denmark)
  - Merging the two in the late 1960s/ early 1970s
  - Adding that services should counteract possible stigmatisation in the 1990s

BACKGROUND – PRACTICAL ISSUES

- The problem: Expansion of special care systems without reduction in waiting lists (1960s)
- Solution: Change the generic services to cater for a wider set of people
- General trend: Strengthening of local governments as service provider
  - Transfer of several services to local governments (1970s and 80s)
  - A prerequisite for the unanimous decision in Norway ("this is not radical at all, but rather in keeping with a substantial set of recent reforms")
- Institutions changed from
  - The preferred option
  - Unwanted but necessary – triggering normalisation of institutions
  - Unwanted and unnecessary –community care came to be seen as a realistic alternative

MAIN RESULTS – LIVING ARRANGEMENTS

- A new generation of group homes – individual clustered living
  - Full individual apartments (50 sqm)
  - The principle of the small group (maximum group size: 4-5)
  - Guiding principle I: the national housing authorities' general guidelines for adequate housing for single-person households
  - Guiding principle II: ordinary housing on residential streets
- The social consequences of clearly improved housing standards:
  - Staff: Reduced level of conflicts between fellow residents
  - Family: It now feels like a visit to the home of our son or daughter, not a ward
  - More like a home

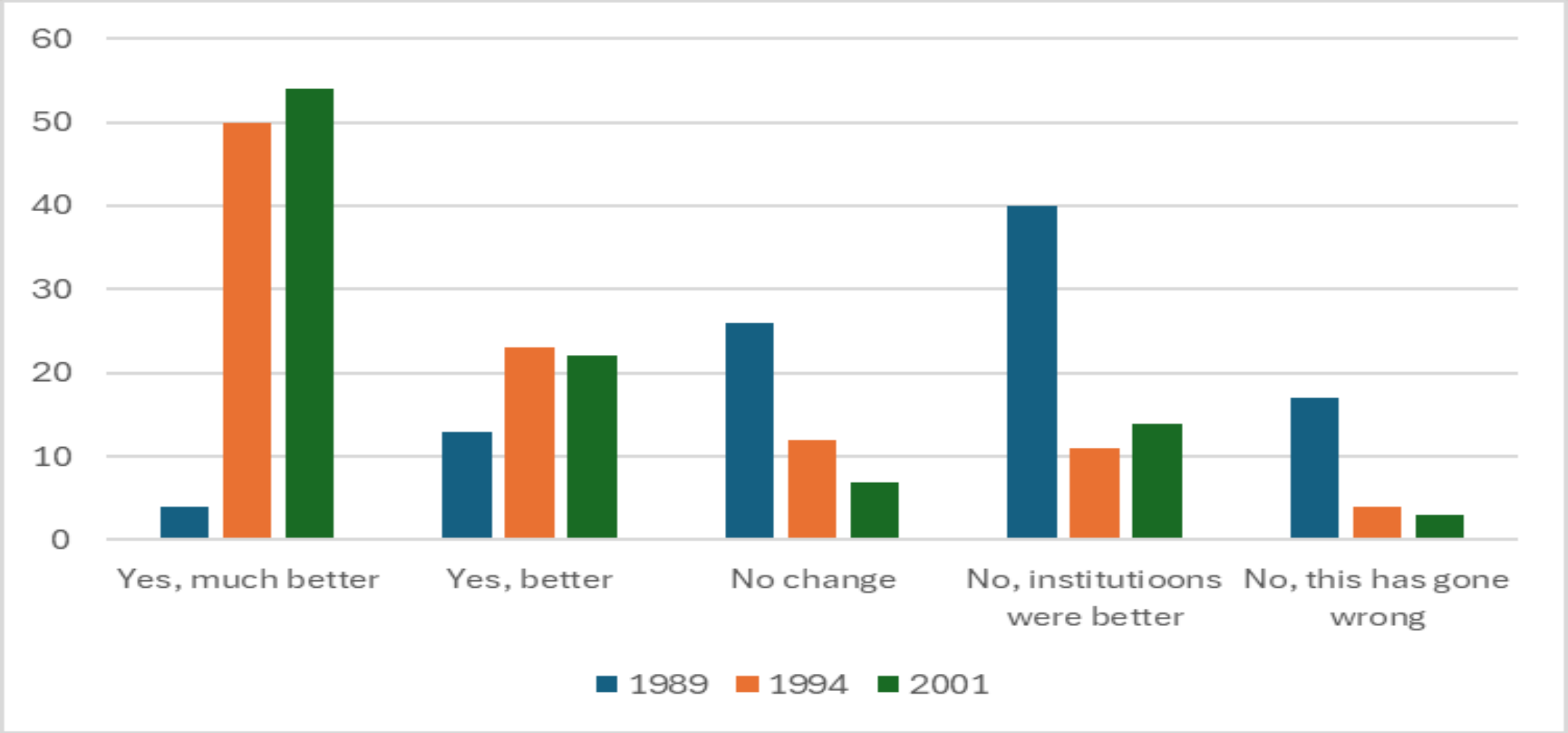
OTHER OUTCOMES – OR LACK OF RESULTS

- Few changes in social networks
  - More family contact
  - Loneliness was much discussed – but did not increase
  - Acceptance in neighbourhoods but not integration
- Few changes in daytime occupation, employment
  - But was meant to be a long-term development
- More people received services, fewer adults stayed with their family
- More self-determination in everyday issues
- Normalisation and individualisation as professional guidelines

FAMILY PERSPECTIVES

- The initial perspective: Scepticism and opposition
  - Lack of trust in local governments
  - Which municipality? "He has not lived there for 35 years!"
  - Compromise, many stayed in the municipality hosting the earlier institution
- After resettlement: Strong support, particularly regarding the new housing
- Ten years after: Continued support
- Dilemma: the pattern of distrust changing into support is typical. Does that mean that one can disregard the initial scepticism?

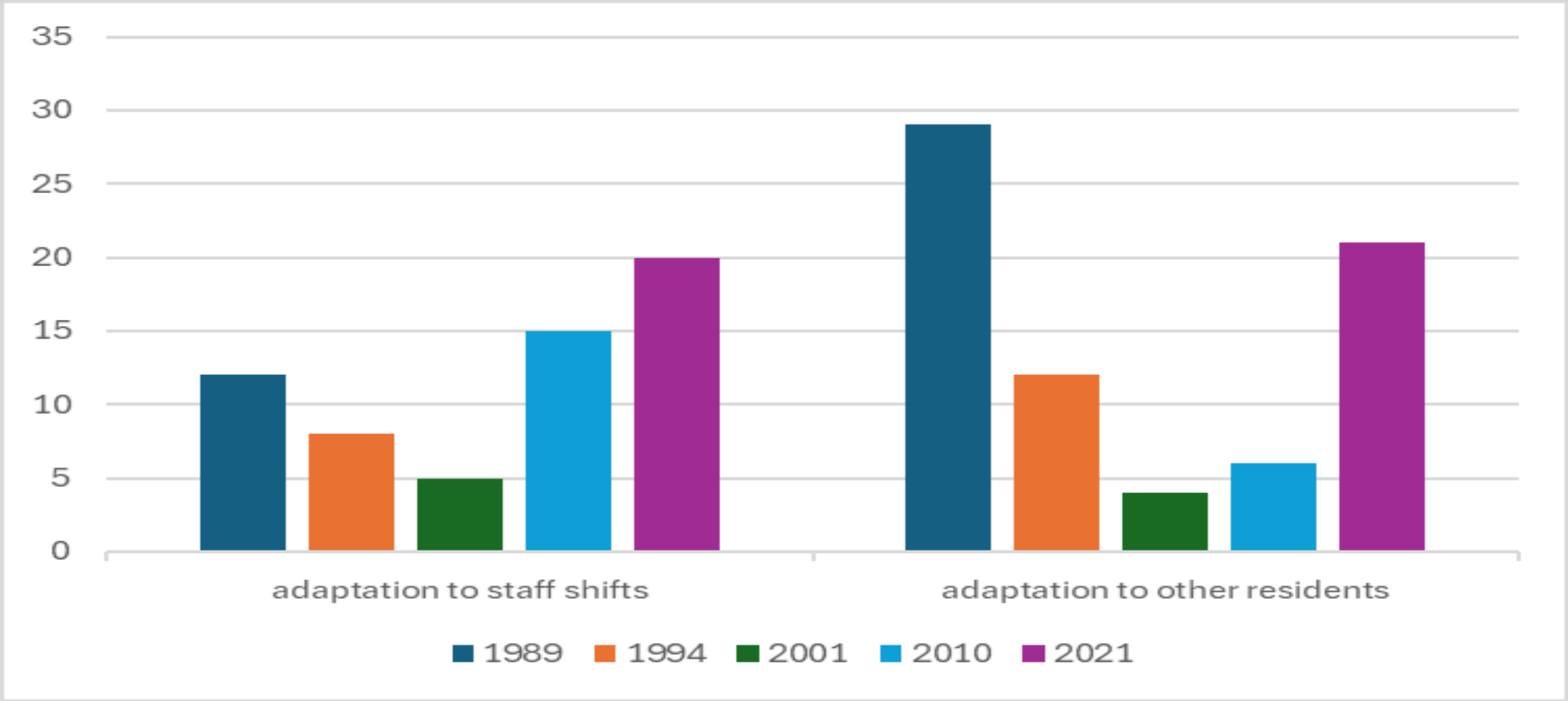
FAMILY ATTITUDES: BEFORE, AFTER AND TEN YEARS AFTER



DIVERGING DEVELOPMENTS AFTER THE REFORM YEARS

- Living arrangements
  - Farewell to the principle of the small group: Mean group size from 3.8 to 9.1 (2021)
  - On residential streets? From clustered apartments near institutions to care ghettoes
  - Economic hardship due to renting costs and disappearing housing benefits
- Employment
  - The promised and expected development never took place
- Self-determination:
  - The issue taken more seriously
  - Indicators of less individualised care – reasons for lack of self-determination
- Other: few changes
  - But clearly a more visible part of the "societal landscape"

REASONS FOR LACK OF SELF-DETERMINATION
(STAFF RESPONSES)



CONCERNING DEVELOPMENTS – HOW COME?

- Changing policy aims? No
- Disappearing national regulations – local government autonomy
- Disappearing attention – no longer on the political agenda
- The practical situation of local governments
  - A fiscal crisis and a search for cost-saving measures
- A change in policy focus – from groups with poor living conditions to the heath and care system providing services (from citizen to patient) (dedifferentiation)
- National contextual changes
  - From "groups lagging behind" to "limits of the welfare state" and coproduction
  - From decentralisation to local autonomy and managerial accountability

THE GOVERNANCE SYSTEM AND DRIVERS OF CHANGE

- The role of politicians
  - From national to local
  - Strategic role, leaving details to the administration
  - From political to administrative accountability
- Professionals
  - National: tired or retired
  - Local: From watchdog to employee responsible for budget control
  - Exit, voice, loyalty
- Consumers
  - Organisations weak at the local level
  - From organisational to individual participation – "take it or leave it"
- Benchmarking: From better than Sweden to "race to the bottom"

LESSONS TO LEARN

- Reforms in services for people with intellectual disabilities need to be safe-guarded (for times with less political and media attention)
- The mission is never accomplished
- There is a need for continuous political accountability
  - Accountable for policy aims
- There is a need for support from general developments (like welfare state ideas or decentralisation)
- Don't forget the quantum leap during the reform years. The reform itself was important, the silence during follow-up problematic

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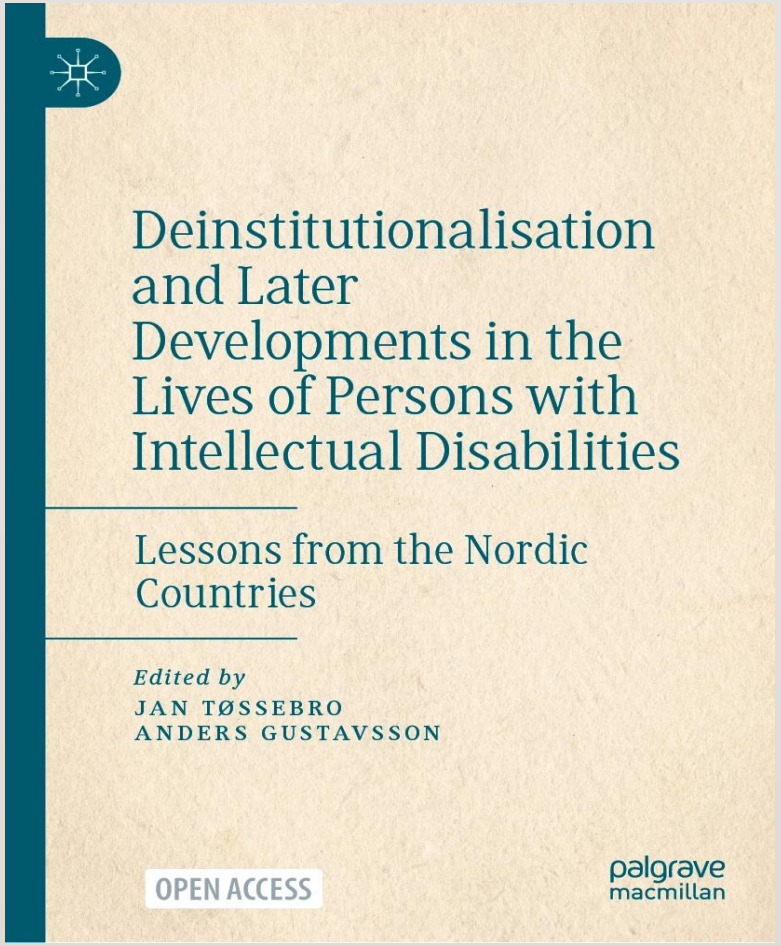
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