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Categorization, self-advocacy and the welfare of negotiation - people with intellectual disability and the current situation in Sweden

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ABOUT SWEDEN



- ABBA, Ingmar Bergman, Björn Borg, The Noble price
- 9.8 million inhabitants
- Large public sector financed through taxes
- Gender equality
- The principle of normalization (Nirje 1969)

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Bild 1

Office1 skriv titel och universitet

Microsoft Office-användare; 2015-11-01

Three types of welfare state

	Liberal	Social democratic	Conservative
Dominant locus of solidarity	Market	State	Family
Modal examples	USA	Sweden	Italy

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Sweden 1980

Sweden 2016



Universality

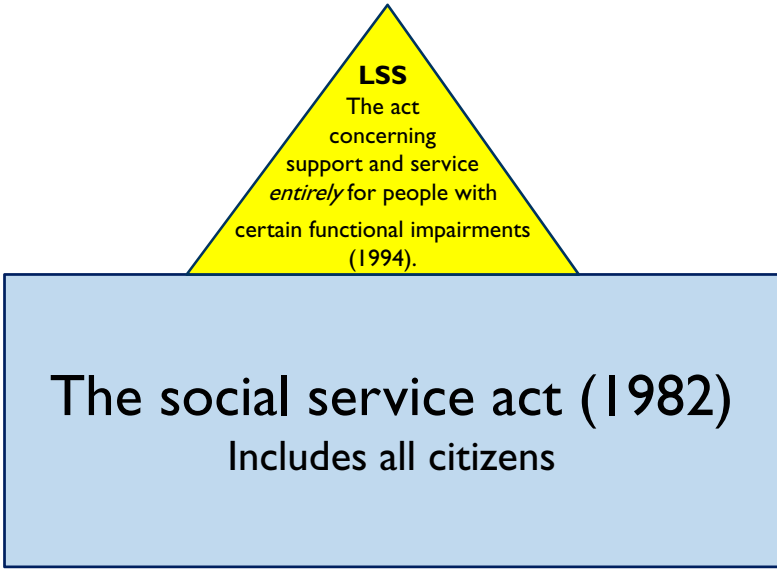
- Benefits and services available for all.
- No means testing.

Selectivity

- Support only for those who are identified as in need.

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LSS
The act concerning support and service *entirely* for people with certain functional impairments (1994).


The social service act (1982)
Includes all citizens

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DISABILITY POLICY

- LSS = The act concerning support and service for people with certain functional impairments
 - 10 entitlements
- 50 000 children and adults with ID
- Government structure: the state, 21 county councils and 290 municipalities



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2016

- Children with ID growing up with their parents (with support from the society)
- Children with ID participate in the same preschool groups (age 1- 6) as other children
- Education: Children with ID get their education in same buildings as pupils without ID (but mostly in separate classes as pupils in a special programme)
- The institutions were closed in 2002



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After institutions?

- Adults with ID live in their own apartments (with support) or in group homes (with staff, part- or fulltime)
- Research identified three types of group homes (4-6 persons/group home):
 1. Family-oriented
 2. Network-oriented
 3. The small institution



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Work

- Most adults with ID have some occupation - daily activities or paid employment
- Activity grant (age 19-30) and after 30 a low pension from the state
- Locked-in effect
- Increasing supported employment and social enterprises



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Important challenges and trends

Living conditions - Significant differences remain

1. A growing number of young people categorized as people with intellectual disability
2. An increasing variation in achieving support and services
3. Resistance - Self-advocacy



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Bild 10

A1 Do you mean accessing?
Admin; 2015-11-03

I. Increased categorization

- A significant increase of children and youth as intellectual disabled since 1995 (more than doubled)
- Higher demands in school, decreasing of resources
- Limited knowledge about the long-term consequences of categorization



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2. Variation in services

- Decentralization of responsibility
- Market principles
- Ability to negotiate
- Advocates
- Private for-profit companies



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3. Self advocacy

- Resistance and empowerment

- 60 self advocacy groups in Sweden
- Same basic motif: increase the participation
- Two competing organizations: Klippan (The rock) - closely connected to the parent's organisation (40) and Grunden (The grassrots) - independent (20)
- Supported by the society
- Active Self-advocacy groups: 17 Klippan and 13 Grunden

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Case study: 4 self advocacy groups (2 from Klippan and 2 from Grunden)

- Personal benefits – new relations, new roles, new identities, more confidence – impact outside the group
- Important for members' personal situation
- Few self advocacy groups have developed political agendas
- The relation between members and supporters and the supporters' approach important
- Life time for a self advocacy group about 7-8 years

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Opportunities

- Dedicated key members and supporters
- Regular meetings
- Accepting and supporting climate
- Feeling of solidarity
- Supporting partners

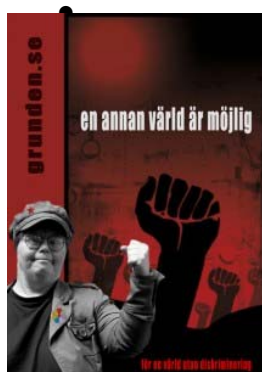
Obstacles

- Lack of leading key persons
- High average age
- Meetings with more focus on form over content
- Lack of respect within the group
- Lack of partners

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No more shit! An other society is possible...



[Grunden Sheriff - YouTube](#)

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Conclusions

- Policy emphasis on self advocacy in the transformed welfare state
- A growing number of self advocacy groups, but only 1/3 active
- 1/3 independent – 2/3 inside the parents organisation
- Important impact on the individuals during a period of years
- Leadership, regularity and allowable climate
- Emphasis in the literature on the 'political' aspect of self advocacy rather than the 'personal' but more of personal agendas than social movements
- Identity of resistance (Castell 1997)
- Impact on attitudes and treatment?
- A limit life time

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Improvements and setbacks

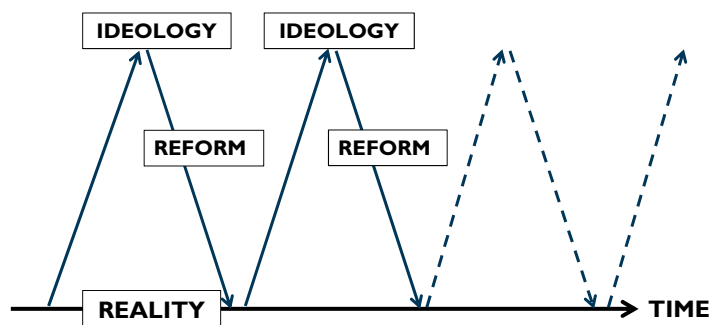
- Closed the institutions, right-based legislation, people with ID more visible and present in society
- You have to fit in to the system
- Support and services depending on where you live and who you are
- A welfare of negotiations
- Staff - No demands for education or competence
- Fragmented disability movement



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A role model or a warning example?



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“The normalization principle means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.”

(Bengt Nirje)

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“The degree of democracy in a society is directly dependent on how politics, economy and morality relate to their vulnerable groups”

(Sven Grassman)

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Gustavsson, A, Sandvin, J, Trausadottir, R & Tøssebro, J (eds) (2005). *Resistance, reflection and change – Nordic disability research*. Lund: Studentlitteratur

www.socialstyrelsen.se

RAPIDD – Swedish Disability Research – what lessons for Australia?

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