Impact of identity and every-day life
- People with intellectual disability and self-advocacy in Sweden

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Self-advocacy (SA)

Are Self-advocacy-groups a way of increasing power and participation in local society, or just a new version of a segregated activities for people with ID?
• Increased numbers of SA-groups the last 20 years in Sweden
• In accordance with the disability policy and the changes in welfare systems
• Emphasis on choice and self-determination
Aims

• The meaning and importance of engagement for the members daily life
• The organisational character of SA-groups
• SA-groups and influence on local disability politics
Methodology

Mapping of all self-advocacy groups in Sweden

- Case studies of 6 self-advocacy groups
- Observations of activities
- Semi-structured interviews with 26 self-advocates and 6 support workers.
- Interviews with 6 local politicians/representatives
- 2 Focus groups (with other self-advocacy groups)
- Two-day conference with 60 self-advocates
SA-groups in Sweden

- 30 self-advocacy groups
- Two national organizations:
  - Klippan (the Rock) – part of the parents’ organisation
  - Grunden (the Grassrots) – independent
- Supported by the society
- Promote self-determination and increase the participation in society
Active

- Dedicated key members
- Regular meetings
- Accepting and supporting culture
- Teamwork and solidarity
- Supporting support workers

Less active

- Lack of leading key members
- High average age
- Meetings with more focus on form over content
- Steering support workers
Identity

“The word ‘developmental disturbed’ disturbs me! We are an association for people who are being called intellectual disabled – We are all valuable and must get rid of all prejudices and labels”.

“My self-confidence has increased. Everything has changed in my life. Today I see myself as one who can speak up when something is wrong. Today there are no differences between me and X and Y. And sometimes I am the one who helps”
Social capital

“I always felt lonely previously.. I never thought I should get as good friends as I have today”
Cultural capital

“I use my new knowledge, in most contexts. Also in my private life and outside the association”
Self-determination

“At that time it was others who decided. I couldn’t decide by myself. But today I’m the one who make the decisions”
Impact on local disability politics?

Interviews with 6 local politicians/representatives:

- The SA-groups are active
- Information activities to the general public and politicians/officials
- The importance of people speaking up themselves
- Some examples of impact on already made decisions (reactive)
- No examples of proactive impact
- User-committees: Recognition but also risk for less influence
Conclusions

• SA = the third generation of disability organization (Bylov 2006)
• SA-groups contribute to visibility and recognition of people with intellectual disability.
• Self-advocacy is important for daily life and identity, but to various degrees.
• The belonging to a group with the goal to have power in the society, strengthen the self-determination and self-confidence.
• Recognition as individuals and as a group, but still not full societal recognition (Honneth 2012)
• Emphasis in the literature on the ‘political’ aspect of self advocacy, but mostly personal agendas in focus.
• Many SA-groups fade out after 5-7 years.

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