



# 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?



**grundens.se**

## mänskligare rättvisare

### Resan till en mänskligare och rättvisare värld !!!

#### Grundens Filosofi

Föreningen Grunden är för oss som har intellektuellt funktionshinder. Vi arbetar fria från kommunerna och föräldra- organisationer. Grunden ägs och kontrolleras av oss själva. Bara personer med intellektuella funktionshinder kan vara medlemmar med rösträtt.

Vi arbetar i Grunden i Sverige och i People First Europe.

Vi vill ha respekt och tillit och bli bemötta med värdighet.

Vi måste ha tillgång till byggnader, information, idéer, språk och ord.

Vi vill bestämma själva och ha inflytande över allt som rör oss.

Vi måste ha tid och coaching för att kunna vara med på allvar.

Vi arbetar mot all sorts diskriminering och utanförskap på grund av funktionshinder, hudfärg, religion, språk och sexualitet.

Vi arbetar mot stämplingar och vi kräver att bli bemötta som värderade personer med alla de mänskliga rättigheter varje medborgare har.

Vi vill vara med i hela samhället och dela ansvar med andra.

Vi har samma känslor, tankar och behov som andra.

Vi behöver vara med och höra till.

Vi har behov av mening i vårt liv. Vi behöver kärlek och närhet.

Vi behöver växa, utvecklas och förändras.

Vi behöver betyda något för andra.

Förstås är vi emot alla sorters institutioner, stora som små.

Ingen människa skall behöva bo på institution.

Vi svar att vi tillsammans med alla människor med intellektuella funktionshinder i Sverige, Europa och hela världen skall kämpa tillsammans ända till vi är fria från utnyttjande, fria från förtryck, fria från institutioner och diskriminering.

Anna Strand

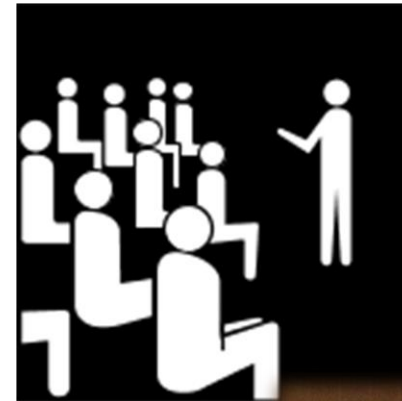
för en värld utan diskriminering

- 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 Grassroots) – 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”.*



# Recognition

*“ 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.

Thank you

Mineur, T., Tideman, M., & Mallander, O. (2017). Self-advocacy in Sweden—an analysis of impact on daily life and identity of self-advocates with intellectual disability. *Cogent Social Sciences*, 3(1), 1304513. doi:10.1080/23311886.2017.1304513

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