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SOCIOLOGY | RESEARCH ARTICLE

Self-advocacy in Sweden—an analysis of impact on daily life and identity of self-advocates with intellectual disability

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Abstract: Self-determination and the ability to express opinions and preferences are fundamental to all people. Some people with intellectual disability no longer accept a subordinated role as disabled and new self-advocacy groups have evolved. The aim of this study was to analyse the meaning and importance of engagement in a self-advocacy group for self-advocates daily life and identity. An interpretative abductive approach was used to analyse data from interviews with 26 self-advocates from six self-advocacy groups in Sweden in relation to the theoretical concepts; recognition, social capital, culture capital and self-determination. The key finding is that the vast majority of the participants experienced a changed self-perception, as more skilled, social and confident people, depending on group affiliation, their personal engagement and positions within the group. The conclusion is that self-advocacy is important for daily life and identity of people with intellectual disability. The self-organized movements indicate an important change in society and the results are of importance not only for the target group but for shaping future support and treatment from society of people with intellectual disability.

Subjects: Development Studies, Environment, Social Work, Urban Studies; Social Sciences; Behavioral Sciences

Keywords: intellectual disability; self-advocacy; identity and belonging; attitude change; attitudes; empowerment approach; self-determination; self-esteem; Sweden

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PUBLIC INTEREST STATEMENT

Self-determination and the ability to express opinions and preferences are fundamental to all people. More recently it has become more common that young adults with intellectual disability organize themselves so they together try to increase the power over their own lives and at the same time influence the local society in the direction of increased participation. This study aims to, through case studies of six self-advocacy groups in Sweden, increase the knowledge about how the participation in self-advocacy can influence the members' identifications, self-determination, relationships and daily life. Its main findings show that the participants experienced a changed self-perception as more skilled, social and confident people. The self-organized movements indicate an important change in society and the results are of importance for the target group and for shaping future support and treatment from society of people with intellectual disability.

1. Introduction

Self-determination and the ability to express opinions and preferences are fundamental to all people, including those living with disability. Self-advocacy among people with disability has primarily been described as an opportunity to have a say and to develop skills to do so (Goodley, 2000, 2005). In some studies, the “People First” definition is used, which includes the right and possibility to speak up for oneself as well as being entitled to make choices, to be independent and to take responsibility for oneself (Anderson & Bigby, 2015; Aspis, 1997). It also covers campaigning at the collective level regarding issues of importance for the group (Goodley, 2000).

Self-advocacy groups have been given attention in several international studies (e.g. Anderson, 2013; Anderson & Bigby, 2015; Aspis, 1997; Beart, 2005; Beart, Hardy, & Buchan, 2005; Chapman, 2014; Goodley, 2000, 2005; Llewellyn & Northway, 2008; Poetz, 2003; Shakespeare, 1993), but what characterizes self-advocacy groups in a Swedish context has previously not been very frequently studied. The aim of this study is to explore how the importance of engagement in a self-advocacy group for people with intellectual disability is experienced by self-advocates as well as impact on identity and everyday life.

The study explicitly focus on self-advocacy among people labelled as intellectually disabled, which often has been referred to as an identity with a master status (Becker, 1997 in Kittelsaa, 2014; Dorozenko, Roberts, & Bishop, 2015). It has also been revealed that those with an intellectual disability identity comprehend negative characteristics which may explain why many people labelled as intellectually disabled not identify themselves with the label (Beart, 2005; Beart et al., 2005; Finlay & Lyons, 1998; Jahoda, Wilson, Stalker, & Cairney, 2010; Kittelsaa, 2014; Klotz, 2004). People labelled as intellectually disabled also question other people’s way of identifying them, and creates their own more positive identity—as ordinary people (Jahoda et al., 2010; Szönyi, 2005). In studies where self-advocates own perspective has been prominent, the importance of being involved in a self-advocacy group has been studied in regard to new opportunities and the development of new skills and social roles (Poetz, 2003) as well as positive identities (Anderson, 2013; Anderson & Bigby, 2015; Svensson & Tideman 2007). The findings of these studies among self-advocates from UK and Australia showed that self-advocates had opportunities to engage in new activities, making new friends and thereby prevent loneliness and boredom, but also opportunities to be an important person by holding important positions within the association. To be more confident, new positive social identities—such as being an “expert, a self-advocate, a business-like person and an independent person”—were proved to be of importance (Anderson, 2013; Anderson & Bigby, 2015). Similar findings emerged in a Swedish study by Tideman and Svensson (2007, 2015), who also stated that participants perceived an increased sense of well-being.

The importance of individual’s attitudes and belief in their own ability to define and reach their individual goals have been shown by Ward and Meyer (1999), a result which also can be related to other people’s, not least support-persons, attitudes and support in developing this belief and exercising the right of self-determination (Goodley, 1997). In addition, the role of support-persons in self-advocacy groups has been stated as complex by Chapman (2014), embracing both a person-centred and a collaborative approach to promote a team-work and avoid a “them and us” division.

Goodley (2000) has pointed out that the degree of independence varies considerably between self-advocacy groups, and identified different models of self-advocacy. The autonomy model has been described in a more idealized way (Buchanan & Walmsley, 2006) while other models, such as self-advocacy groups within the service-system, have been criticized for the risk of comprising control of what the self-advocates’ have a say about (Aspis, 1997).

In the Swedish context people with intellectual disability still experience social injustice and exclusion in society, although normalization and inclusion have been the political guiding principles for decades. However, some people labelled as intellectually disabled no longer accept the subordinated role as a disabled person in society (Tideman & Svensson, 2015) instead they choose to refuse

support from the welfare society (Barron, 2004; Ringsby Jansson & Olsson, 2006) and new self-organized associations have evolved (Svensson & Lundgren, 2002).

The purpose of this study was to describe and analyze (a) the character of self-advocacy groups in Sweden (Mallander, Mineur, & Tideman, *in press*), (b) if and how self-advocacy groups were perceived to have any influence on societal changes (Mineur, Mallander & Tideman, *submitted*), and (c) the meaning and importance of engagement in a self-advocacy group for the participants' daily life and identity—the result of which is reported in this paper. The specific research questions were: In which ways and to what extent are engagement in a self-advocacy group experienced to have an impact on self-advocates' daily life and identity? How can similarities and differences be understood, related to the characteristics of the groups?

2. Method

Drawing on ethnography and a weak social constructionist perspective (Bhaskar & Danermark, 2006; Danermark, 2001; Gustavsson, 2004) the primary data was collected by semi-structured interviews with self-advocates connected to six different self-advocacy groups. In addition, meetings and activities organized by the groups were visited and observed on several occasions. An interpretative approach, based on hermeneutic theory (Gustavsson, 2000), was used to analyze the data. The findings were discussed with all the participants at a concluding conference. The study was approved by the Regional Ethical Board (in Lund, Dnr. 2013/117), in Sweden.

2.1. The self-advocate groups and interviews with the participants

For an overview of the steps and stages in the methodology see Figure 1.

The study involved self-advocates from six self-advocacy groups, who were connected to two different nation-wide organizations referred to as *Klippan* and *Grunden*. The first one, *Klippan*, has similarities with the model, named by Goodley (2000) as the divisional model, since it is a part of the Swedish parents' organization for children, youth and adults with intellectual disability (FUB, after its Swedish abbreviation), who also advocate for the group. *Grunden* have no such connections, instead *Grunden* emphasize the importance of self-advocacy as a way of counteracting others' often historically paternalistic ways of advocating for the group and exhibit traits similar to the autonomy model—related to the People First movement in the UK context (Goodley, 2000).

All groups were visited and observed before the interviews were conducted. The observations served to get obtain information of the groups, as well as the participants, and to increase our understanding of what they were doing during their meetings and activities, and how they actually were doing it. In addition, it was also of importance to establish trusting relationships, before the interviews were conducted (e.g. Angrosino, 2004).

Figure 1. Method overview—sample, data collection and analysis.

1. Mapping all self-advocacy groups in Sweden belonging to two national organizations
2. Telephone contact with every group (n=60)
3. Sample of six, three from each national organization, based on diversity of activity, number of members and geographical location
4. Repeated observations at the six groups and establish trusting relationships.
5. Individual interviews with 26 participants with intellectual disability (for details - see table 1 and table 2)
6. Analysis of the interviews in relation to theoretical concepts
7. Comparison of analysis from the interviews with participants from the same self-advocacy group
8. Analysis of all interviews from self-advocacy groups belonging to the same national organization
9. Comparison of findings between the two national organizations
10. Discussion of findings in 4 focus groups to improve the trustworthiness
11. Discussion of findings with all participants at a concluding conference

When the aim of the project was introduced to the participants, we also offered the opportunity to be interviewed. Self-advocates who volunteered were the ones who were interviewed, some key persons were also asked if they wished to participate, for example the chair- or spokesperson of the group. Additionally, oral information about the research project was given to the participants when a support-person of the group was present. All participants were also given written information about the study, and before they gave their written consent they were informed about their right to withdraw from the study.

During our first visits in the groups, when information about the study was given, discussions were held with participants to gain an understanding of which questions they thought should be included. Most of the self-advocates were interested in questions of a more practical nature, for example how meetings and activities were conducted in other groups, something we took into account and are reporting in a companion paper (Mallander et al., *in press*). At a concluding conference where all participants were invited and the interviews' results were presented and discussed.

Individual interviews were conducted with 26 self-advocates from six groups, three were Klippan groups and three were Grunden groups (Tables 1 and 2).

The interviews covered the following areas: *When and why they attended the group, the meaning and importance of attending the group, in regard to; group affinity, activities, relationships, knowledge and new possibilities and finally advocacy work.* All interviews were conducted in the associations' premises, apart from a few exceptions, since some of the participants chose to be interviewed at home. During the interviews a map of the themes of the interview were used, to support the participants in understanding what we were supposed to talk about (Thomsson, 2010). Pictures of activities in the specific groups, as well as quotes from the vision and objectives of the associations were also used as helping devices. The interviews lasted from 30 min to two hours; they were all recorded and transcribed verbatim.

2.2. Analysis and theoretical concepts

The analysis, which builds on an interpretative approach and hermeneutic theory, can be described as a process whereby we oscillated between the whole and the parts of the self-advocates' experiences, a process which aimed to reach a meaningful and holistic understanding (Gustavsson, 2000).

Table 1. Overview of Grunden groups, interview persons and their positions in the group

Grunden groups	Activities	Wage allowance daily activity/volunteers	Support-persons	Self-advocates being interviewed
Grunden 1	Meetings and campaigning	Yes/Yes/No	Two part time	Lil (LG1) spoke person
				Diana (DG1) spoke person
				Nick (NG1) chair person
Grunden 2	Meetings, campaigning and social activities	Yes/Yes/Yes	Several part time	Rosie (RG2) chair person
				Liz (LG2) board member
				Olivia (OG2) member
				John (JG2) board member
				Carl (CG2) member
Grunden 3	Meetings and social activities	No/Yes/Yes	Two part time	Betty (BG3) vice chair
				Isa (IG3) secretary
				Susie (SG3) board member
				Tess (TG3) board member
				Nora (NG3) board member
				David (DG3) chair person
Richard (RG3) board member				

Table 2. Overview of Klippan groups, interview persons and their positions in the group

Klippan group	Activities	Wage allowance/daily activity/volunteers	Support-persons	Self-advocates being interviewed
Klippan 1	Meetings and campaigning	No*/No/No	Several part time	Frida (FK1) board member Leo (LK1) board member Daniel (DK1) chair person
Klippan 2	Meetings and occasional campaigning and social activities	No/No/Yes	One part time	Joel (JK2) chair person Tom (TK2) vice chair
Klippan 3	Meetings and social activities	No/No/Yes	Several part time	Vilma (VK3) board member Cecilia (CK3) board member Amy (AK3) member Mia (MK3) member Filip (FK3) member Kevin (KK3) member

*But economic compensation for meetings.

Our analytical strategy fits the first steps in latent content analysis (Graneheim & Lundman, 2004) by an initial coding starting when the transcribed interviews were read through (Burnard, 1996). This resulted in five content areas: *Membership, Friends and social relationships, Personal development, Decision-making* and finally *Disabilities and attitudes* under which interview quotations, called meaning units, were sorted. Each meaning unit were condensed, coded, categorized and then grouped and collapsed together in new tables to be interpreted at a higher abstraction level in relation to four significant theoretical key concepts; *recognition, social capital, cultural capital* and *self-determination*. These concepts seemed to be of particularly importance in regard to the self-advocates' experiences of changes in their daily life and their identity. The concept of identity is lacking a precise definition but from a sociological perspective the term is sometimes used interchangeably with self. However, in this study we have used a more manageable way by separating the ideas of self and identity, a division which corresponds to the concepts; social- respectively personal identity (Beart et al., 2005; Giddens & Sutton, 2013). Hence social identity refers to attributes, like being a mother or disabled which are most often covering more than one attribute at the time, picking up strands that unite an agent with other individuals i.e. possessing a collective dimension. While personal identity covers the unique attribute of an individual, a self is in constant change although some strands are more stable and resistant to change than others.

During the continuing process of the analysis our key concepts came to be used through an abductive approach, as specific analysis units (Alvesson & Sköldberg, 2009), to deepen our understanding and to explore the variation of experiences in regard to what self-advocates had in common and what set them apart. What unites the four concepts, used to increase the understanding of changed identities, is that they all have a collective but also an individual dimension. What sets them apart is that they are magnitudes of qualitatively different kinds. Social capital and cultural capital (Bourdieu & Passeron, 1990), as well as self-determination, are expressing capacities of the operators, while recognition is a prerequisite for developing those capacities and the cultivation of these. One might argue that recognition is a necessary but not sufficient condition for the mentioned capacities to develop. According to Honneth (2012) the individual dimension of recognition has an emotional character, being developed in the primary and close relationships by love and friendship. Without recognition there are limited opportunities at the individual level to create the self-confidence needed in acquiring new abilities like cultural skills plus having the courage to use them. Strong cultural capital is an important source for self-advocates to create changes and for their capabilities to act in new ways (Coleman, 1988). The same applies for the autonomous individual and collective decisions (self-determination) a long with making new relations and actively using these (social capital). The concept of self-determination covers the right to have control and have an influence over

central domains of everyday life and contradicts the traditional ideas of people with intellectual disability as unable and dependent. As such it is an important claim as self-advocacy aims to achieve, both individually and collectively (Rojas Pernia, 2006). Finally, social capital refers to relationships which can be used as resources for individuals or groups and thereby serve as a support in different situations or to gain advantages in everyday life (Coleman, 1988; Putnam, 2000). The importance of social capital is dependent on the number of social relationships, or contacts between people, in addition to the kind of relationships and the strength of trust in these relationships, i.e. weak and strong ties (Granovetter, 1973). At a collective level groups or networks are described in terms of being thick or thin, which can be related to their willingness and ability to strengthen the social capital within or outside the group, i.e. bonding respectively bridging (Putnam, 2000).

The analysis process aimed to reach a final interpretation supported by the substantial parts of the empirical material (Gustavsson, 2000). In addition, four focus group interviews were conducted, with two Klippan and two Grunden groups, aiming to discuss the results of the individual interviews and thereby increase the credibility of the final findings. As the results emerged, they were discussed within the research group but also with self-advocates and researchers outside the group to improve the trustworthiness of the study (Kvale & Brinkmann, 2009). The research project was concluded by a conference where all participants in the study were invited to discuss the findings and to develop new important research questions.

3. Findings

Engagement in a self-advocacy group was shown to be of importance for self-advocates who experienced changes in their daily life and identity, but to various extents and in different ways. A majority of self-advocates described themselves as ordinary people; “like everybody else”, but with some difficulties in certain situations, something they argued they had in common with many other people. However, the vast majority of the participants experienced a changed self-perception due to their engagement in a self-advocacy group, as a more skilled, social and confident person.

In the following sections key quotes are being used to illustrate the findings. To begin with, the meaning of a changed identity is clarified, and the implication of a collective identity is emphasized. It is followed by sections where the perceived changes in the participants’ identity and daily life are clarified in regard to the theoretical concepts: *recognition*, *social capital*, *cultural capital* and *self-determination*.

3.1. Changed identity

Experiences of self-advocates in the study suggest that their perceived changed identity are foremost related to their self-perception, which in turn can be linked to their engagement in a self-advocacy group. The collective dimension of identity comprises a shared collective identity within the group they are affiliated to. Answering the question; *who are we?* The answer to that question can be related to the fact that the definition of intellectual disability is not unambiguous, and in addition different Swedish concepts are being used. The Swedish equivalent to the English concept intellectual disability is being used as a synonym to the Swedish official concept “utvecklingsstörning”. It raises problems to give a literal translation of this Swedish term. The definition is “mentally developmentally disturbed”, a concept which brings along a number of negative connotations. The point here is that the concept—by stressing a “disturbance”, i.e. a pathological, condition - goes beyond the pejorative meaning attached to e.g. mentally retarded formerly used in the English-speaking world which has to do with being mentally or intellectually disabled but not disturbed (cf. Bachke, 2006).

The Swedish official terminology has been the subject for discussions and criticism for decades, but the concept has also been defended; by for example the parent organization FUB, arguing that this is the best alternative offered, but lately it has come to be questioned by many of its own members. In this study, a majority of self-advocates in Klippan groups and all self-advocates in Grunden groups, expressed their criticism of this term and stated that it is ambiguous. John explained why he thought it was a strange concept, he said; “one is not disturbed in one’s development, because you

have a normal function, and you can have children”. Among several self-advocates the criticism also highlighted the discriminatory nature of the label.

D: It's a lot of people in today's society who says “developmental disturbed” to everything. Sometimes when I'm sitting at the bus I hear young people saying; “fucking developmental disturbed”, in their cell-phones, it's a lot of bad words being used sometimes, I think (DG3).

It is especially the “disturbance-part” of the word which caused many self-advocates' angry reactions and underpinned their attempts to influence their social environment to change its use. As Joel expressed it; “I try to influence the others here. The word ‘disturbed’ disturbs me!” When he was asked if anyone listened to his criticism he answered; “Yes, many of the members [in Klippan], but I think the ordinary FUB board [members without intellectual disability] has some difficulties with that ... They are stuck, in the old days...” (JK2).

The importance of what concepts being used was something self-advocates had become more aware of since they had been members in a self-advocacy group. Although intellectual disability is the concept a majority of the self-advocates' preferred, it was rarely used when they talked about themselves as individuals, instead it was used to describe the group. Or as the association Grunden states in their statutes: “We are an association for people who are being called intellectual disabled” which actually is a statement against labels. Altogether the unclear definition and the different concepts being used created a kind of indistinctness about who may be a self-advocate for the group. However, this indistinctness also created a space for self-advocates, primarily in Grunden groups since they had no connections to the parental organization, to make their own definition and to adapt it to fit in with their self-presentation. The main thing, as some of the self-advocates' in Grunden expressed it, was the *lived experience* of living with a disability. When we asked if it matters what disability that might be, they broaden their definition of intellectual disability.

L: No, I think as long as someone has the disability. For me it doesn't matter what disability ones have, if one use a wheel-chair, if it is cerebral palsy or Downs syndrome, or what else you have, all are valuable, that's what we work for in Grunden, to get rid of all prejudices and stuff (LG1).

Even though arguments like this disclose good intentions there are risks involved since different groups might have differing needs and requirements in society. On the other hand, it seemed to be of importance for self-advocates be making their own definition, since it meant that the “we” was created by them and not imposing by others and could therefore be the basis of a strengthened togetherness.

3.1.1. Recognition

The self-advocates' experiences of becoming acknowledged and respected as individuals and as a group was a prerequisite for their development of a changed self-perception as well as for their belief in what they as a group could accomplish. These kinds of experiences can be captured by the concept of recognition (Honneth, 2012; Honneth & Heidegren, 2003). Recognition is constituted by experiences and perceptions of others' attitudes and treatment, and emerges in relation to other people, but also by the legal conditions and the prevailing values in a society. Self-advocates described their experiences of the individual dimension of recognition in terms of appreciation, respect, care and consideration.

T: I never thought I should get as good friends as I have today. They care about me, about whom I am and it means a lot to me. I always felt lonely previously and I was used by friends, my former classmates. I'm so glad having friends who cares about me, I think that's why I'm as healthy as I am today (TG3).

A majority of the participants claimed that others' consideration and belief in them had helped them to grow as people and to strengthen their belief in themselves. But some also stressed a

development of their own skills in interacting with other people; “I have learned to have a greater understanding of people. /.../ As persons we are all different but I don’t care much about what disabilities people have, instead I try to figure out, how is this person?” (JG2).

Experiences of being acknowledged as competent persons were common within the self-advocacy groups, not only on basis of the tasks they actually performed but also by the confidence in their abilities shown by their co-workers and support-persons.

N: My self-confidence has increased and that’s something I will carry with me. Because they [other self-advocates] do believe in me and that’s why I came here because they believed in me and thought I could do this. And then others started to believe in me (NG3).

The support persons were of great importance for the self-advocates’ experiences of recognition. An important starting point for the experiences by self-advocates in Grunden was the view of each other as co-workers and equals, which was clearly stated. They all claimed to have a coaching approach, which meant that it was not only the support-persons who were supposed to coach or support the self-advocates’ in their work; instead it depended on the situation. Sometimes self-advocates coached each other and sometimes self-advocates coached the support-persons.

L: Before, when I had daily activity I was treated like shit... they talked to me as if I was 5 years old even though I was in my twenties /.../ Today I notice that there are no difference between me and X or Y [name of the coaches], we are colleagues and they never talk to me in a special way /.../ and sometimes I am the one who helps X (LG1).

Lil was also one of those participants who had experienced how her work within the association had changed others’ way of treating her including people outside the association, such as professionals as she had met in her work and importantly, her closest family.

L: I used to feel very small [small as a cultural] in my family, I did not have very much to tell them and they were not perceiving me as one of them [as an equal], but they have seen me change, I have a job today /.../ everything has changed in my life. Today I see myself as one in the family, as the other kids [her siblings] (LG1).

Lil had become recognized as an important person, which of course played a crucial role for her self-perception and the development of an increased self-confidence, expressed by Lil as; “My self-esteem and my self-confidence is at its peak today” (LG1).

Even though many self-advocates had experiences of being acknowledged for their work within the association there were still occasions when self-advocates at an individual level had become the target of abusive treatment by people in the surrounding community, due to their disability; “Many people just ... ‘well, you have a diagnosis, so you will not make it’ /.../ And they don’t even know me” (DK2). The ones who had these kinds of negative experiences often explained it as a symptom of the ignorance regarding disabilities which still exists amongst some people in the community.

A common experience was that they still had not achieved societal recognition as a group, in terms of getting their societal rights fulfilled in a satisfied manner. Experiences of injustice and discrimination in comparison with other groups were commonly expressed irrespective of group affiliation. However, among several self-advocates the constant pursuit and struggle for recognition through political action was seen as the strength of the association.

J: I can speak up when I think something is wrong /.../ but it is not everybody who have the courage to do that and not everyone can. And for them, we must stand up and make their voices heard. It’s really important! (JG2).

When some self-advocates, Diana for example, talked about issues like this it seemed as though experiences of recognition were related to Grunden as an association rather than the population of people with intellectual disability; “I have politicians on Facebook and now all the politicians know what Grunden is ... and they are positive” (DG1). However, it is of course of great importance to not underestimate the value of self-advocacy groups being recognised as trustworthy associations by for example the authorities. People with intellectual disability, through history, have rarely been seen as capable of advocating themselves, so this is a significant change.

3.1.2. *Social capital*

Creating a social network and thereby opportunities to share experiences and work for changes for individuals and the group, is a central part of the activities in self-advocacy groups. The pattern which emerged in our study showed that engagement in a self-advocacy group gave rise to an increased number of social relationships for a majority of the individuals. Most often it referred to a growing and strengthened network within the self-advocacy group. Members also experienced the deepening of already existing relationships, which sometimes resulted in social activities outside the self-advocacy group.

S: We've had ladies night at my place, me and [names of other self-advocates]. We have cooked together, but sometimes the dinner has been ready when they've arrived and sometimes X [name of some of the other self-advocates] has stayed and slept at my place (SG3).

The activities, in Grunden groups, comprised both work and leisure time. Some self-advocates were employed by wage allowance employment and some fulfilled their daily activity within the association. As shown in the example given above, some of them also spent a great deal of their leisure time together. The relationships between self-advocates in these groups often seemed to be characterized as strong. In a few cases these strong ties were used as a resource to increase self-advocates' personal autonomy outside the group. In some cases, when self-advocates had experiences of being a victim of paternalistic approaches by staff at their group-homes they brought along another self-advocate and a coach to discuss the situation, advocating for a change at the group home. When we visited one of the Grunden groups we were told about some of these cases and how they had followed up afterwards and discussed the situation within the group to confirm that there had been improvements.

The amount of time the participants in Klippan groups were engaged with each other as self-advocates was limited, since Klippan groups are solely leisure time associations. This meant that the relationships within Klippan groups at first sight could be characterised as a “thin” social capital (Putnam, 2000). However, in the smaller municipalities, self-advocates interacted with one another in other places, since some lived at the same group home or fulfilled their daily activity at the same work place, which meant that the time they spent together in a Klippan group could offer opportunities of strengthen their already existing relationships. For some self-advocates these strengthened relationships also offered opportunities to get to know new friends.

M: X [name of another member] is a member of Klippan and I have come to get to know her better by Y [another member]. /.../ Well, I don't know ... [how], but I have come to get to know a few more people (MK3).

There were also examples of self-advocates who increased the number of “weak ties” (Granovetter, 1973) outside the group, by an increasing network on Facebook; “I have got an increased social network nowadays, since I became a member of the association. /.../ Especially at Facebook, I am a Facebook nerd” (BG3). For some of the participants Facebook was used not only to increase their social network but to get in contact with people holding specific positions in society. Diana for example used it as a means to be in direct contact with the local politicians; “Previously I didn't know how to use it [Facebook] to be in contact with others, but now I know for example how to reach the

politicians” (DG1). The amount of time self-advocates were engaged in their groups seemed to be of importance for their opportunities to make new contacts outside the association, i.e. bridging, which was more common among self-advocates in Grunden groups. Primarily, these “weak ties” outside the group were used to reach an increased understanding of the prevailing circumstances for people with intellectual disability in the broader community.

3.1.3. Cultural capital

The vast majority of self-advocates experienced an increased knowledge within several fields, as a result of their engagement in the self-advocacy groups. It can be referred to as an increased cultural capital comprising increased knowledge, abilities and skills (Bourdieu & Passeron, 1990). Self-advocates expressed their increased skills as important in many different situations.

L: I’ve learned a lot by Grunden, I know a lot more nowadays than in the beginning. /.../ The meaning of concepts ... respect and trust ...

I: In what contexts can you use this knowledge?

L: In most contexts /.../ also in my private life and outside the association (LG2).

Increased knowledge was often described in terms of how the work was carried out, not to mention how they were supposed to act within the association, not least as members of a steering board where decisions were to be made; “I have learned a lot. Previously I couldn’t talk as I can now. I’ve learned that you should talk to the end ... One should not interrupt people, that something I’ve learned” (VK3). In addition, an increased knowledge regarding a political awareness concerning general disability issues, such as the economic situation for people with intellectual disability and their right to participate in society were expressed among several self-advocates, especially in Grunden groups. When experiences of increased knowledge were discussed with Betty she described the knowledge she had developed, in terms of; “A lot of different legal rights and that people should have a decent life /.../ I have a more equal view of life now, like every cultural being is equally worthy” (BG3).

Moreover self-advocates experienced a development of their relational abilities. These were manifested in an enhanced ability to interact with others and to have the courage to do things they usually not did, e.g. become engaged in discussions, receive criticism and try to explain what they meant instead of becoming quiet if they were contested. “In the beginning I couldn’t handle constructive criticism, nor negative criticism, but nowadays I can handle these things” (LG3). Interaction skills also covered capabilities of collaboration, by Joel expressed as he had become; “able to collaborate with others and things like that. And I dare to stand up and talk to people /.../ it’s a lot that you know ... you have learn ... like new words” (JK2).

Self-advocates also expressed the view that they experienced increased well-being, an improved self-perception, and an increased self-confidence. Not everyone could put into words what exactly they had learned and in what ways they had changed as a person, instead they talked about it as a feeling of being different from before; “I feel like I have become a completely new Tess!” (TG3). It included an increased belief in their ability to handle different situations, among many self-advocates expressed as; “I do have increased my self-confidence” (LK1).

As in a previous example in which Nora is quoted, improved self-confidence not only stems from increased cultural capital in terms of developing new skills, abilities and an greater courage to act in different situations, it also highlights recognition as a prerequisite for a changed self-perception. In addition a strengthened self-confidence also meant that some self-advocates no longer pretended to know things they didn’t, expressed by John like this; “I’ve learned that you should not be afraid to say, ‘I do not understand, explain this to me’” (JG2). This was an important knowledge in itself since John for example had become aware that an approach like this meant an opportunity to actually learn even more. Previously in this paper, we have also argued that recognition is a prerequisite for

developing new capabilities but it is also true in the reverse direction. This is shown in findings in which self-advocates had experienced, at an individual as well as at a collective level, the ways in which increased cultural capital changed others' attitude and approach to them as individuals and/or as a group; "I am being treated well; I am being treated by more respect now, since I know about legal rights, and such things" (BG3).

The collective dimension of cultural capital refers to joint and shared knowledge and abilities. By discussing societal rights and improving self-advocates knowledge and awareness regarding these issues, the collective knowledge could be used as a source to rise important questions for the group, something that is closely related to the collective dimension of self-determination.

3.1.4. Self-determination

The concept of self-determination covers the right to have control and make an influence over central domains of everyday life and contradicts the traditional ideas of people with intellectual disability as unable and dependable. The collective dimension of self-determination refers to the right to have a say about the well-being of the group at a societal level. Some self-advocates' did argue that they, through their position in the association, were able to take action to make changes in society regarding this kind of issues; "I know that I can change things. But above all I have an influence in making things better in our society" (LK3). For some self-advocates, like David for example, this was one of the main reasons why it was important to be engaged in a self-advocacy group.

D: I think it is important to try to make people feel good. /.../ we are no Gods I use to say, but we try to help people [with intellectual disability] who might have problems with authorities, we try to help as much as we can (DG3).

Irrespective of group affiliation it was primarily self-advocates holding important positions who claimed that their engagement in a self-advocacy group was of importance not only for them as individuals but also for the opportunity to support others.

At an individual level, increased opportunities for self-determination were shown by the extent to which self-advocates felt they had gained more control and influence over their lives. Engagement in a self-advocacy group was, by many self-advocates, experienced as the best opportunity to exercise this societal right.

S: I think Grunden is good for me, since I want to be as independent as possible and I want to be sure of myself so I can ask questions about why things are as they are in the society. Sometimes I think there's an inequity in the society (SG3).

A majority of the participants had experiences of confined opportunities for self-determination during their lifetime, but for many this had improved in later life. With increased cultural and social capital and improved self-confidence, the opportunities of raising these types of claims and actually exercise self-determination were more likely to be achieved.

T: We've learned how to vote [within the self-advocacy group]; we've learned how to write ... proposals. We've got to know each other better, in this way. We've learned ... well, all that. To then be able to take our own decisions (TK2).

What Tom refers to is the capacity of decision-making within the association, instead of relying on support-persons opinions or suggestions. Increased cultural capital, in terms of knowledge about cultural rights in line with an improved self-confidence was also of importance for self-advocates personal decision-making regarding issues in their life. For some there were opportunities to just act without first asking, as for example Joel successfully had done;

J: I decided that my wife should move in with me. We did not give a damn about the social worker... we did not even go through the social worker. We started to change her address, via the tax authorities. And when she was written at my address, then the municipality ... had to take it seriously. /.../ if we had went directly to the municipality and said that we would like to ... then they had said no, it cannot be done ... (JK2).

The exercise of self-determination was also related to an increased social capital. It was foremost the strong relationships within the association, primarily in Grunden groups, used to assert individuals' right to make decisions in their own life. Sometimes, as has been highlighted previously in this paper, by involving support-persons and co-workers in issues occurred at their group-homes. However, in some cases relationships outside the association were also used as a resource. Managers of social services known to the self-advocates were for example invited to meetings with the group to be informed about deficiencies, e.g. at a group-home, and were then expected to take action; "We talk about what we can do [within the group, to support members], maybe we talk to the authorities or we contact the unit manager or something like that" (DG3).

Self-advocates expressed an increased awareness of their right to exercise self-determination. For some it was realised through their work within the association, while their opportunities to exercise this right in their private life still remained limited since they had to adapt to rules made up by others, for example at the group homes. Tess claimed that she was the one who decided in her life; "No one else has anything to do with my life, it's only myself" (TG3). Tess, who was in need of support in her daily life, explained during her interview the schedule for her support, a schedule which also included what she was supposed to do, for example housekeeping at Thursdays. When asked what happened if she couldn't do the housekeeping during a Thursday she answered; "But I have to!" (TG3), since it was the only day she could receive sufficient support for that task in accordance with her schedule. Other self-advocates had made more progress however, not only claiming their right of self-determination, they had also been able to exercise that right in their daily life.

L: When I had daily activities I had nothing to say. At that time it was others who decided, I couldn't decide by myself, but today I'm the one who make the decisions (LG1).

Lil was one of the participants who were employed, by a wage allowance in her self-advocacy group, something that had been of great importance for how she perceived her opportunities to be the one who made important decisions in her daily life. A different role meant that she saw herself and perceived to be seen by others as a competent co-worker instead of a care-taker who were totally dependent on others.

4. Discussion

Engagement in a self-advocacy group in Sweden was shown to be an important factor of influence on self-advocates' daily life and perceived changed identity. The key concept; identity is lacking a precise definition, but in this study a definition distinguishing between social- respectively personal identity is used (Beart et al., 2005; Giddens & Sutton, 2013). Self-advocates' experiences were interpreted through the theoretical concept of recognition, social capital, cultural capital and self-determination. Changes in the social or collective identity were primarily focused on the understanding of what constituted "the we", which importantly had to be defined and conceptualised by the group and not by others (cf. Goodley, 2000). There were examples of an increased strength and belief in what they as a group could accomplish, while a perceived changed personal identity foremost referred to a changed self-perception, as a more skilled, social and confident person. These findings are consistent with previous research revealing that self-advocates, through their engagement in a self-advocacy group, became more confident and saw themselves in new, different ways (Poetz, 2003), through positive social identities (Anderson & Bigby, 2015).

It is important to emphasize that our findings show that engagement in a self-advocacy group were of importance for all participants, but it would be incorrect to say that it had the same

significance for all of them. However, it would also be a mistake to argue that some self-advocates have experiences more valuable and important than others, but to increase the knowledge of self-advocates various experiences it is interesting to discuss how the prevailing differences can be understood. Some previous research about self-advocacy have been discussed the importance of it being radical or political (Aspis, 1997; Goodley, 2005) and thereby be raising questions of legal rights (Aspis, 1997). Other researchers have argued that self-advocacy is a way for individuals to develop a positive self-perception, and thereby be able to handle and in the long run even influence and change prejudices in their social surroundings (Beart, Hardy, & Buchan, 2004). Opportunities, which must not be underestimated (Anderson & Bigby, 2015). In the present study it was established that it was primarily self-advocates in key organisational positions who were involved in self-advocacy work aiming to create changes for the group at a societal level. The very same self-advocates were also more likely to describe increased opportunities of speaking up for themselves. Moreover these persons were the ones who devoted the most amount of time for self-advocacy work. The variation in objectives and ambitions among self-advocates are of course an important basis for the understanding of the prevailing differences. Engagement in a self-advocacy group as a way to make friends and thereby prevent loneliness are not less important for individuals, but it didn't seem to have an equally extensive impact on self-advocates daily life and identity, in comparison to self-advocates who engaged not only for their own sake but also to advocate for the group and to work for improvements at a societal level. Something that can be understood by the fact that people who are given (or who are taking) increased responsibility in their lives are growing with the task and the implied role, e.g. as a chair person. Those in such roles in the self-advocacy organisations seem to have more opportunities to develop cultural and social capital but also to be recognized by others for the work they do. All are important and contribute to perceived changes in their lives. These findings, in line with findings in previous research (Anderson, 2013; Anderson & Bigby, 2015), reveal the importance of formal positions for the development of a positive identity. Steering committees including different office-bearer positions seem to be one way of organising self-advocacy groups. It seems also important to consider and value the roles of all of the members of self-advocacy groups and work to ensure that those unable or unwilling to take on management roles in the organisation are not excluded from opportunities for personal development.

One part of this project aimed to analyse the character of self-advocacy groups in Sweden (Mallander et al, *in press*). In those findings it was shown that significant differences between the organisations of Klippan respectively Grunden groups existed. Some of the self-advocates' various experiences can be related to what group they were affiliated to since different organisational approaches meant that self-advocates were facing different opportunities and expectations in actually being the ones who were advocating for themselves and for the group (cf. Goodley, 2000), something that influenced the likelihood of being recognised for their work. Klippan groups were primarily shown to be leisure time associations and the social dimension was certainly an important reason to why many of their participants had chosen to engage in a Klippan group, offering an opportunity to increase their social network (Mallander et al, *in press*). But perhaps more importantly it meant an opportunity to strengthen ties to people they have known since before, as their relationships often could be characterized as multiplex relations (Gluckman, 1967, in Coleman, 1988) as they often met at the same daily activity and sometimes also lived at the same group home. Advocacy work that meant contacts with representatives of the community was, on the other hand, more often upheld by advocates without an intellectual disability. This differed from the circumstances in Grunden groups, which comprised both work and leisure time (Mallander et al, *in press*). In addition to the strong ties prevailing among self-advocates and the characteristics of bonding at a collective level, Grunden groups were also characterised by bridging (Putnam, 2000) which meant that they to a higher extent were the ones who through their work in a self-advocacy group made contacts outside the association and also experienced that they as a group were being recognised for the work they carried out.

The parent organization FUB emphasizes people's disabilities, difficulties and differences in comparison with other people as a way of ensuring the legal rights of the group. These identity features are seen as a prerequisite to having their societal rights fulfilled. As a part of FUB, Klippan groups

seemed to be organized in a way which reflects a similar approach (Mallander et al, *in press*). Together with FUB, Klippan groups have the potential to be a strong voice in the social debate on issues of importance for the group, but this organizational approach also contains a certain level of risk. As with other models of self-advocacy, e.g. within the service-system (cf. Goodley, 2000), people without an intellectual disability may be the ones setting the agenda, while self-advocates are expected to act as their legitimising voice (Aspis, 1997), instead of being the ones demanding to have a say about the issues they find most significant.

The work in Grunden groups seemed to be building on a rather different approach in comparison with Klippan groups. In the Grunden groups self-advocates' disabilities or difficulties were not becoming the point of departure, when the work was being planned or performed. Instead, Grunden's guiding principles of equal rights in society, the way as they wished to work and ideas of uniting factors among people in general served as a starting point. This was also reflected in the way their support was designed, which meant that they most often referred to each other as co-workers and they were all expected to have a coaching approach, resemble with a collaborative approach where members different strengths are being recognized (Chapman, 2014). However, this approach did not work without complications; it often required adaptations while the work was in progress and sometimes also meant a failure, and occasionally it was causing internal conflicts (Mallander et al., *in press*). Still, even failures might be interpreted as a part of a learning process, of importance for an increased individual as well as collective cultural capital and thereby an improved self-confidence. In previous research it has been stated that engagement in a self-advocacy group entails an opportunity for the participants to be something more than a person with intellectual disability, put in other words; an opportunity to "write and rewrite their own 'identity script'" (Anderson, 2013, p. 160). An opportunity which partly can be related to the extent to which the social identity as intellectually disabled is being defined within a self-advocacy group (Dorozenko et al., 2015), as an identity factor with a master status or not.

5. Conclusion

Some people with intellectual disability no longer accept a subordinated role as disabled and new self-advocacy groups have evolved. The aim of this study was to analyse the meaning and importance of engagement in a self-advocacy group for self-advocates daily life and identity. An interpretative abductive approach was used to analyse data from interviews with 26 self-advocates in relation to the theoretical concepts; recognition, social capital, culture capital and self-determination. The findings showed that the vast majority of the participants experienced a changed self-perception, as a more skilled, social and confident person, depending on group affiliation, their personal engagement and positions within the group.

Recognition by others in their self-advocacy groups was shown to be an important factor in achieving this change. Participants experienced recognition for who they were as a person, i.e. something more than solely a person with intellectual disability, but rather as a cultural being, an equal with other people. However, a common experience among all participants was that people with intellectual disability as a group still had not achieved societal recognition in terms of getting their societal rights fulfilled in a satisfactory manner, i.e. the legal dimension of recognition, which according to Honneth (2012) is crucial for the development of self-respect. How the authorities are thinking about opportunities for the self-advocacy groups to have an influence on societal improvements for people with intellectual disability is an important question. Perceived prejudice still held by the community is an issue which not only can be challenged by self-advocacy groups. Instead, this issue needs to be addressed both within and outside groups, building on an interaction process based on mutual recognition between self-advocacy groups and their social network. Other important findings discussed and further confirmed during the concluding conference were self-advocates' experiences of creating new and strengthening existing relationships as well as improving cultural capital (cf. Coleman, 1988). This discussion also included reflections on the prevailing differences between the groups regarding opportunities to actually advocate for oneself, not least in relation to their need for support and how the support best can be designed and developed, something that need to be

investigated further. It can be concluded that different organisational approaches shouldn't be a question of what is right or wrong, but should reflect an awareness of the fact that the precondition within a group will have an impact on whom the advocates can be, not to mention on what they will accomplish as a group. With that as a tenet self-advocacy groups need to clarify their goals for themselves and what they want to achieve in terms of socialization or/and political mobilization, and how it best can be done.

This study is not without its limitations. The sample is limited to self-advocacy groups which are part of national organizations. To address this, future studies should make a conscious effort to recruit a broader sample of self-advocacy groups, including Internet-based and free-standing groups. Another limitation is the lack of critical or negative opinions on self-advocacy. Future studies may wish to specifically target participants in such a way as to ensure they are drawing the attention of those who hold both positive and negative views of self-advocacy.

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