Self-advocacy for people with intellectual disability in Sweden – organizational similarities and differences

Ove Mallander
Malmö University, Sweden

Therese Mineur
Halmstad University, Sweden

David Henderson
La Trobe University, Australia

Magnus Tideman
Halmstad University, Sweden and La Trobe University, Australia
Email: Magnus.Tideman@hh.se

Abstract

Self-determination and the ability to express opinions and preferences are fundamental to all people. Self-advocacy (SA) among people with intellectual disability (PwID) presents opportunities for them to develop skills to have a say and influence changes in their local environments. The aim of this article is to explore and understand organizational similarities and differences of SA groups for PwID in Sweden by focusing their structures and activities. Within the theoretical framework of Resource-Dependency and New Institutional Perspectives, data from six Swedish SA groups belonging to two different national organizations, have been analyzed. Factors such as affinity and expectations show limited differences, while power distribution, rules and the role of support persons point to greater diversity. However, good relations within the local organizational field seems to be essential to maintain strong SA for PwID.

Introduction

The concept of self-advocacy (SA) for people with intellectual disability (PwID) is difficult to define, but in its most literal sense, it means speaking up on one's own behalf and deciding what is best for oneself (Williams & Shoultz, 1982). A more fully developed interpretation of self-advocacy draws on broader principles of civil rights and self-determination. As such, self-advocacy is concerned with ensuring that people with intellectual disability can have a say about issues important to them, but it is also concerned with building individual (and collective) capacity among people with intellectual disabilities. Goodley, for instance, has described
self-advocacy primarily as an opportunity for people with intellectual disabilities to have a say and to develop their skills to do so (Goodley, 2000; 2005). Other scholars have argued a similar point, suggesting that self-advocacy is about the right to speak up for oneself, to make choices, to be independent and to take responsibility for oneself (Aspis, 1997; Anderson & Bigby, 2015). Most scholars acknowledge that self-advocacy plays an important role in the lives of people with intellectual disability and many argue that engaging in self-advocacy can, to some extent, be an empowering process (Anderson, 2014; Walmsley & Downer, 1997).

An overview of the international literature demonstrates that self-advocacy groups have received some significant scholarly attention (for example, Anderson & Bigby, 2015; Aspis, 1997; Beart, 2005; Chapman, 2014; Goodley, 2000, 2005; Llewellyn & Northway, 2008; Mineur et al, 2017; Poetz, 2003; Test et. Al, 2005). However, the focus of this research has varied considerably. Some researchers have explored the educational goals underpinning the self-advocacy movement (Wehmeyer & Schwartz, 1997), while others have explored the link between self-advocacy and self-determination (Field & Hoffman, 1994; Wehmeyer & Berkobien, 1991). Others still have argued that self-advocacy groups are best understood as part of a broader social movement (Cone, 1999; Williams & Shoutitz, 1982). These studies have shown how self-advocacy groups are important because they foster new opportunities, teach new skills, and create new social roles for people with intellectual disability (Poetz, 2003). The findings of these studies have also indicated that self-advocates who engaged in new activities made new friends, developed more confidence, and assumed new, more positive, social identities and roles (Anderson, 2014; Anderson & Bigby, 2015; Svensson & Tideman, 2007; Tideman & Svensson, 2015).

Although often highlighted in the international literature, self-advocacy for people with intellectual disability has received much less scholarly attention in Sweden. One seminal work by Hugemark & Roman however (2012; see also 2008, 2005) touched on the topic of self-advocacy and uncovered some similarities between the experiences of people with intellectual disability and other oppressed groups, such as women and sexual minorities. In their study, Hugemark & Roman analyzed six different disability groups, one of which was a self-advocacy group for people with intellectual disability. The aim of the study was to explore how these groups worked to foster a sense of collective identity among their members, what kind of obstacles these groups met in their work, and how the concepts of injustice and oppression were understood and articulated by the members of these groups. Hugemark & Roman (2012) found that these six organizations defined, and sought to achieve social justice in quite different ways, and also that different organizational approaches had some effect upon how each group accessed resources and gained political legitimacy. While Hugemark & Roman compared differences between various disability organizations, the purpose of this article is to explore and understand the significant differences within the Swedish self-advocacy movement for PWID itself.

In Sweden, there are two national self-advocacy organizations, Klippan and Grunden, and each organization has sought, in its own way, to facilitate greater self-determination among its members with intellectual disability. Klippan is an auxiliary of the Swedish National Organization for Persons with Intellectual Disability (Swedish abbreviation: FUB), which is essentially a parent run organization that was established in the 1950s. Since its inception, the FUB has been committed to advocating for, and improving the lives of, people with intellectual disability. Anyone supporting these broad goals can become a member
of the FUB and anyone can be elected to the national board, although regulations stipulate that at least one person with an intellectual disability must be a board member at all times. In 1995, many FUB members with intellectual disability argued that the organization did not allow them genuine opportunities to communicate their own views and experiences. As a result, the FUB created Klippan – a self-advocacy network of which only people with intellectual disability could be members – that nevertheless continued to operate as an auxiliary of the FUB. While this solution, consistent with Hirschman’s (1970) voice-concept, satisfied some FUB members with intellectual disability, others considered it too limited and argued that they would be better served if they severed ties with the FUB completely. As a result, a second national self-advocacy network, Grunden, was established around the same time by those who felt they could no longer work within the FUB (Hugemark & Roman 2008:38). Andersson, who gave a brief account of this messy emancipation process in 2002, traces the roots of this split back to the 1970s and the recurring debate around the power-deficit of people with intellectual disability in most parent run organizations (cf. Armstrong, 2002).

On the surface, the Klippan model of self-advocacy shares many similarities with Goodley’s (2000) divisional model of self-advocacy in that it remains closely affiliated with a predominantly parent run organization, the FUB. By contrast, Grunden, like People First in the UK, is essentially an autonomous organization run by, and for, individuals with intellectual disability. As such, the Grunden model of self-advocacy shares a closer resemblance to Goodley’s so-called ideal model of self-advocacy. To our knowledge, no scholar has systematically compared the essential characteristics of these two quite different models of self-advocacy in the Swedish context. It is this gap in the research that the present study seeks to address and it will do so by focusing primarily on the structures and activities that underpin the operation of the various Klippan and Grunden self-advocacy groups across Sweden. More specifically, the purpose of this analysis of Swedish self-advocacy is threefold. First, this study seeks to analyze and describe the specific character of the two biggest self-advocacy organizations in Sweden. Second, it aims to gauge the importance of self-advocacy for the participants’ identity and the role that self-advocacy plays in their daily lives. Finally, this study seeks to explore if, and how self-advocacy is perceived to have had any significant influence on engendering lasting social change in Sweden. The findings are reported in this article.

Theory

Two similar theoretical frameworks, Resource-Dependency Perspectives (RDP) and New Institutional Perspectives (NIP), provide a solid basis for understanding certain operational aspects of the Klippan and Grunden models of self-advocacy. The RDP and NIP theoretical frameworks are both essentially concerned with understanding an organization in terms of its adaption to its environment or to its organizational field (DiMaggio & Powell, 1983; Johansson, 2006; Fligstein, 2007; Wooten & Hoffman, 2008). In order to survive, every organization must acquire legitimacy and power, as well as resources from its environment (Pfeffer & Salancik, 1978; Hall, 1991). This mutual need to obtain resources creates an interdependency between the studied (focal) organization and its organizational field, where all agencies concerned strive to achieve autonomy and thus avoid a disadvantageous position of dependency. Furthermore, members within the focal organization who possess vital or scarce resources will usually achieve a more dominant position within that organization (Scott 2003). While RDP stresses the material aspect of this relationship (i.e. power and resources), such a perspective
tends, according to Hasenfeld (2010:40), to underestimate the importance of moral values and ideologies that transcend calculations of power and money in organizational behavior.

In NIP, the more ideological elements of a focal organization are highlighted, such as, institutionalized norms, the values and cognitive elements that form its structure, and the manner of thinking and action that informs a focal organization’s approach to its work (Meyer & Rowan 1991, DiMaggio & Powell, 1983). The key concept in NIP is legitimacy, which is usually obtained when an organization, in its actions and structure, reflects the rule-like belief systems prevailing in its environment. Such organizations are thus viewed as social and cultural systems embedded within an “institutional” context.

Method

This study constitutes a case study. As Yin (2009) and others have noted, a case study is often the most appropriate approach to separating a problematic phenomenon from its context. In a case study, a variety of data sets, such as surveys, experiments, interviews or observations, might be included to form both context and argument (Merriam 1998). This study has certainly assembled empirical data from a variety of sources, which ranges from the organizational documents of the Grunden and Klippan self-advocacy networks, to observational studies, interviews and detailed surveys with self-advocates and support staff.

Sample

Table 1 (below) outlines our procedure for the selection and analysis of non-documentary source material. This started with our mapping of the national Klippan and Grunden self-advocacy networks. A second step involved the selection of strategic samples of five Klippan and Grunden Groups. A third step involved a deeper analysis of three case studies from each self-advocacy organization.

1. National mapping of 36 local/regional Klippan and 12 Grunden
   IA groups

2. Strategic samples of Klippan 5 Grunden (high level of activity, different sizes) 100 observation studies

3. Case studies of Klippan at Grunden (face-to-face interviews with 54 self-
   advocating and 54 non-advocates and 340 interviews with self-advocates
   referencing group studies = 4 focus group interviews with self-advocates

Based on lists provided by the national organizations of all existing self-advocacy groups in their organization, 45 Klippan and 12 Grunden groups were identified. A structured telephone survey was conducted with leading members of these Klippan and Grunden groups, where interviewees were asked about certain aspects of the operation of their organization. Respondents from the Klippan groups were, in most cases, self-advocating trustees ("post receivers"), but sometimes support staff. The respondent from the Grunden groups was usually the local chairman of that particular group.
These surveys were supplemented with exploratory key-person interviews at the national level. Working from those key-person interviews, a strategic sample of five self-advocacy groups from each organization was identified that allowed for a second, deeper stage of analysis. During this second stage, each of the five groups was visited at least once and sometimes up to three times and field notes were taken on each occasion. During these visits, a final sample of informants was recruited to participate in further in-depth, semi-structured interviews. To avoid the familiar methodological difficulties of interviewing people with intellectual disability (Angrosino, 2004; Perry 2004; Atkinson 1988), it was important to establish trusting relationships. Thus, interviews were carried out in locations chosen by the self-advocates themselves and this was usually in the offices of that particular self-advocacy group. Interviews covered the following themes: reasons for membership of the self-advocacy group, the importance of membership of the group in regard to group affinity, activities, relationships, knowledge and new possibilities, and finally advocacy work. Interviews, which ranged from thirty minutes to two hours, were recorded and transcribed verbatim, however all quotations used in this article have been translated from Swedish into English in order to capture the essential meaning of the quotation, rather an exact word for word translation.

Finally, it is worth noting that to further preserve the integrity of this study, the five Klippan and five Grundén groups were divided into a case study group, which consisted of three self-advocacy groups from each organization, and a focus group, which consisted of the remaining two groups from each organization. The focus group interviews, which were carried out to the above mentioned interview standards, were aimed at ensuring an effective methodological approach and persevering the credibility of the findings. These findings were presented at a two-day conference at Halmstad University in April 2016, where self-advocates from the ten self-advocacy groups in the strategic sample (60 persons in total) participated and, after further discussion, confirmed the veracity of the findings.

This study was approved by the Regional Ethical Board, Lund University, Sweden (Dnr 2013/117). In addition to requiring informed consent, including written acceptance from all participants, a presentation of the project – preceded by written project information – was held on at least one occasion at each self-advocacy organization.

Analysis

The procedure of condensing and coding the data took place within an abductive framework, which specifies a movement back and forth between empiricism and theory (c.f. Bryman 2012). This methodology is essentially both theory-driven and empirically propelled. Like deduction and induction, it relies on rules of inference, but contrary to those rules, the abduction primarily lacks a formal logical validity (Bertilsson & Voeltmann-Christiansen, 1980). Alvesson & Skoldberg (2009) claim that while most case studies actually employ abduction methodologies, these studies carry within them elements of both induction and theory propulsion, as in the present study.

The main sources of data from this study consist of the organizational documents mentioned above and interviews with self-advocates and support staff. After repeatedly reading through the source material, phrases or sentences of relevance were selected. These phrases, or meaning units, were
condensed and subsequently coded. Relatively open codes were used and – along with the more meaningful quotations – put into arrays based on the model developed by Miles and Huberman (1994). This was done with interview subjects grouped according to their organization, in rows, and sub-themes – either those themes referred to above, or those emerging spontaneously during the interviews – in columns. By clustering material into larger units and constantly modifying these to the documented content of observations and focus group interviews, we settled on the following, partly overlapping, categories for analysis: organization and environment, affinity, self-advocate expectations of the organization, role of support staff, power and decision-making, and member control and the consequences for self-advocates. These categories give structure to the findings presented below.

The pattern of categories for analysis outlined above is comparable to the structure proposed by Ahrne (2013) on social relations in general, and on organizations in particular (Ahrne 1994; cf Ostrom, 1999). However, it differs in three important respects. First, the support person’s vital role in both the Klippan and Grunden organizations was a recurring theme in all interviews and has therefore been treated as a separate category for analysis. Second, the control and the consequences of violations of expectations is considered as its own category for analysis. This is due to the fact that these dimensions are closely connected, but also because the interview data is relatively sparse on these vital issues. Third, the importance of organizational environment is ever present in the documentary data, which motivated us to form a separate category for analysis to properly understand the pertinent issues at hand.

Findings

The Organizations And Their Environment

The Klippan self-advocacy network is, and always has been, an auxiliary of the FUB and it is difficult to gauge exact membership numbers. However, it has been estimated that members of Klippan account for approximately 20-25 percent of the FUB membership base, which stands at approximately 25,000 members (Hugomark & Roman, 2012). The FUB is a hierarchically ordered organization. A central committee oversees the general operation of the national organization, but regional and local level sections take on the day to day operations of the various local groups. The organization of the Klippan self-advocacy network mirrors the top-down, hierarchical structure of the FUB, and funding for local Klippan groups stems from the local FUB chapters to which they are aligned. However, some other minor funding comes from the municipalities in which these groups are located. The support staff are mostly volunteers although some staff members are salaried. Support staff are educated by the FUB and play a key role in maintaining group activities in conjunction with the self-advocates. Local groups are therefore nodes in a limited, stable and nationally similar network of relations dominated by the FUB, but also containing municipalities and some educational organizations.

The Grunden self-advocacy network is overseen by an umbrella organization, Grunden National, and relies on financial contributions from central government agencies that provide resources to the twelve, independent local self-advocacy groups. (Grunden, 2014a). Grunden National has its headquarters in Gothenburg – where more than half of the 900 Grunden members live – and is run by a board whose chairman is also the head of
operations (Grunden, 2014b). Salaried support staff offer ongoing support to
Grunden National and to each local self-advocacy group. All staff are
supposed to share the organization’s ideology. Each local self-advocacy group
has significant autonomy and members may carry out their business as they
see fit, provided it takes place in accordance with the organization’s vision
statement and overarching philosophy. In all Grunden self-advocacy groups
investigated, municipalities were leasing premises to the self-advocacy groups
free of charge or at a considerable discount.

Although essentially independent from municipal and parental influence, the
Grunden self-advocacy network is nevertheless somewhat dependent upon its
collaborations with external partner organizations (Grunden, 2014c). Grunden
National, for instance, has formed partnerships with several municipalities in
Sweden as well as the Swedish Disability Federation. At a local level, the
organizational field differs quite dramatically from one municipality to another,
and some local Grunden self-advocacy groups have formed partnerships with
services providers, disability organizations, local sponsors, schools,
educational organizations, and local disability NGOs. The strength of these
partnerships varies considerably and in most cases, the municipalities remain
the most significant partners in terms of funding and opportunities for
collaboration.

The most influential relationships for local Grunden self-advocacy groups are
at the same level as the vital resource inflow. By contrast, the Klippan self-
advocacy network is subsumed into the hierarchy of the FUB and is therefore
less dependent upon this sparse network of external partners. In terms of
organizational theory, Klippan has a stable and homogeneous organizational
field, whereas Grunden, relying as it does on municipalities, NGOs and
government agencies, is both heterogeneous and somewhat turbulent. Based
on the same theory, one might expect Klippan to have a lower degree of
specialization and higher regulatory operative control. Meanwhile Grunden, at
least at the national level, retains a high degree of specialization to capture the
environmental changes that might be decisive for its continued existence
(Jacobsen & Thorsvik, 2006; Scott, 2003).

**Affinity**

The concept of affinity is concerned with establishing who belongs to an
organization; what bonds link participants to, and separate them from, non-
participants; and also the type of person an organization strives to recruit as
members. With respect to the concept of affinity, the formal difference between
the Klippan and Grunden model of self-advocacy is limited, yet crucial. Anyone
interested in supporting or participating in the activities of Grunden is welcome
do so and membership is open to anyone. By contrast, only people with
intellectual disability can become members of Klippan. But while the statutes
of Grunden stipulate that a board should oversee the operations of each local
self-advocacy group – as well as the umbrella organization, Grunden National –
no corresponding requirement exists for the local Klippan self-advocacy
groups. For members of Klippan, representative positions are therefore
restricted to a limited number of regional or national (but not local) board
positions. In terms of membership, both the Klippan and Grunden
organizations ostensibly target the same cohort, that is to say people with
intellectual disability. However, as pointed out elsewhere (Mineur et al, 2017)
each organization uses different labels to describe those they wish to recruit.
into their organization. Klippan, for instance, uses the label individuals with a "developmental disorder." By contrast, Grunden uses the moniker "people with so called intellectual disability," which emphasizes both the relativity of the delimitation, and the similarity between that group and people with modest, or no, learning difficulties.

In Grunden, the claim of being a spokesperson for the target group outside the organization is less precise but occasionally more far reaching and sometimes extends to "all people with disabilities". Grunden also has a better success rate with their recruitment drives than their Klippan counterparts. Potential restrictions to recruitment can range from the recruit's number of impairments and the extent of those impairments, to the inadequacies of municipal disability services in informing people with intellectual disability of the existence of the Grunden self-advocacy network. For Klippan, the main restriction on recruitment can usually be put down to a general shortage of properly trained support staff.

**Self-Advocates' Expectations Of The Organization**

A precondition of every functioning organization is the shared expectations that underpin the reasons for the organization's existence, for example, for whom the organization exists, the activities the organization engages in, and what rules and standards apply to the operation of the organization (Hugemark & Roman 2012). All informants of both organizations expressed expectations that their organization should serve as a platform for people with intellectual disability to improve their everyday-lives and also offer a social hub in which members might engage in educational or social activities. While the first mentioned expectation has a concretely individual aspect to it – i.e. to support members make contact with authorities or service providers – it is, above all, an expression of a collective concern. And that concern is with influencing politicians, changing public attitudes, and raising awareness about disability issues. These issues might range from the entitlement of people with intellectual disability to fair treatment, to their concerns with being able to access the resources that might compensate them for the difficulties that the group encounters in their daily lives. Hence, there is within both organizations interwoven expectations of recognition and redistribution (Fraser, 2003). Both the Klippan and Grunden self-advocacy networks also aspire to raise the level of political awareness among the members of their organization. However, while only a few Klippan informants were aware of the organization's political agenda, almost all Grunden interviewees used the language of inclusion and empowerment – participation, influence, equality, autonomy, trust and respect – which suggests that the political agenda permeates Grunden more thoroughly than it does Klippan.

All self-advocates cherished the social motives underpinning their self-advocacy groups. And nearly all expressed an understanding of the potential for such groups to act as a platform for social encounters. However, some members of Grunden articulated this expectation in greater detail and linked those activities to the goal of engendering social inclusion. In self-advocacy groups, as one Grunden member put it, isolation and passivity are countered. The similarities between Klippan and Grunden extended to the expectations among members of both groups of the types of activities offered by their groups. These ranged from trips to cafes, Bingo evenings, visits to restaurants and the cinema, and opportunities to engage in study and sports. There were
similarities too in the more ritualised events like spring promenades, Christmas luncheons, occasional summer visits to the theatre and holidays. However, political activism pays a more vital role in the Grunden self-advocacy groups, as do pub evenings. Also, local Grunden self-advocacy groups take responsibility for organizing their own regular dances (some of which are organized in conjunction with local businesses). By contrast, in all cases but one, dances were organized at a regional level or, just as often, organized as a FUB project with the support of Klippan.

Members of both Klippan and Grunden are expected to share the goals of their respective organizations which, as noted, are relatively similar. In Grunden however, there is a stronger emphasis on protecting human rights and on combating all forms of discrimination. Lacking statutes of their own, Klippan nevertheless share a number of other rules in common with Grunden, although these rules have not been codified. When self-advocates spoke about these general rules they often referred to expected codes of conduct within in their organization, such as "never use violence or bully anyone, never say bad words to another, never beg for money". Other rules, however, are more concerned with organizational cooperative codes, like listening, not interrupting, and turning off mobile phones at gatherings. As we will show below, while these two organizations did not differ significantly in their expectations in terms of their rules and norms, they differed quite definitively in their handling of any violations of those rules.

The Role Of Support-Persons

Local Level

The complex role played by support staff in self-advocacy organizations is not easy to describe, much less evaluate. Through individual and collective support, support staff are ostensibly required to compensate for the self-advocates' cognitive difficulties. As such, they might offer self-advocacy groups (or individuals) support in understanding economics or complicated concepts. They might also provide support in written documentation, which self-advocates might use as the basis for making their own decisions. In Klippan, the role that support staff are required to play at meetings is described as follows: support staff shall provide self-advocates "with memory support, explanation, simplification, encouragement, emotional support, recording, preparation, but support staff should not control or disturb the meetings" (FUB, 2015).

Klippan support staff are nearly always volunteers and are constantly in short supply. All support staff undertake training via a short course designed by the FUB. As such, their roles are clearly defined and perhaps because of their training, Klippan staff adopt a similar approach to disability ideology and to people with intellectual disability. The above mentioned lack of financial independence of Klippan self-advocacy groups also means that staff sometimes offer support that goes well beyond their remit. For instance, they might help self-advocates in private matters, such as their choice of clothing or the styling of their hair. This sort of support might even extend to "helping me butter sandwiches", as one self-advocate put it, "because otherwise there will be too much butter". However, self-advocates in both the Klippan and Grunden organizations desire, and do in fact receive, cognitive support
that helps with understanding certain situations and their contexts. This explains, in part, why self-advocates in the both organizations are generally satisfied with how the support system works.

Local Grunden self-advocacy groups have more independence from their umbrella organization, Grunden National, than their Klippet counterparts have from the FUB. Such independence offers local members greater freedom to design the organizational role of their support staff to better suit their needs. As such, the formal role of Grunden support staff, or coaches as they are called by the Grunden self-advocates, is also more fluid. In contrast to the centralized training offered to all Klippet support staff, who essentially follow a script derived from the national FUB model of support, the role of the coach varies in each individual Grunden self-advocacy group. That is to say, the exact role a coach plays rests on a negotiated order, and an interpretation of the coach-concept is carried out based on local municipal traditions, whatever resources are available at that time, and the composition of the self-advocacy group in question. The outcome of this process of interpretation varies considerably from one group to another and can be affected by various external forces. For instance, homogenous forces, like the strength of a coach’s commitment to the ideology of Grunden will inevitably affect nature of their support. Meanwhile, dissipating forces, such as the fiscal responsibilities of each self-advocacy group, will also shape the nature of the support they receive, because each group remains an autonomous, legal entity with a budget that must be balanced each financial year in order for the group to survive.

The presence of coaches at formal Grunden board-meetings is tolerated but coaches are not allowed to vote. However, this ostensibly clear directive does not prevent conflicts arising about the role support staff play in the decision-making process. One chairman of a local Grunden self-advocacy group touched on a tension that exists between the self-advocates’ absolute right to make their own decisions and their dependence on the expertise of the coaches’ support for making their decisions. Coaches “should make corrections if something goes wrong”, the chairman explained, “but they should not interfere and decide on everything.” While no self-advocates offered advice on what coaches might do better, some offered criticism of nature of the support they received. The most ubiquitous criticism concerned the way in which self-advocates tended to become more passive and less talkative when coaches attended board meetings. One board member noted that a process of pacification often occurred when coaches sat in on meetings and what followed as a result was “silence, no one dares to say anything”. Another Grunden board member explained that there was always the risk of coaches violating self-advocates’ self-determination by simply taking charge. He suggested that one had to be careful and:

That’s why no one not having an intellectual disability are allowed to have a seat on the board… because we should be able to make decisions without being influenced by others who then may want to take over.
However both Klippan and Grunden self-advocates relativize their own absolute claim to decision-making in their respective organizations. One Klippan self-advocate reluctantly accepted that occasionally his decisions might be completely altered by the support staff. "Well, it works like this that we make the decisions, the supervisor ... he says 'you said wrong there, it should be like this,' he then tells me". Also, the complexity of certain issues on meeting agendas sometimes forces a participant to acknowledge his or her need for support. "You can see yourself that you need support," one Klippan self-advocate explained, "it is necessary... in order to understand certain paragraphs." The reasoning of one local Grunden self-advocate was more or less the same: "It is up to us [to decide]... but then they (coaches) think they need to take part when we carry out activities too ... so that it will not go all wrong". Although all self-advocates claimed to know what support they required, there was some variety in the self-advocates' understanding of their own role, as receivers of support. Some acknowledged the necessity of asking for help, only when it is needed, while at the other extreme, some expected the coach to anticipate an individual's need for support. For example, one self-advocate explained that "they [the coaches] discover when you need support, I think. It is difficult to see that myself".

National Level

In contrast to the one (or sometimes two) staff members who provide support for an entire self-advocacy group at the local and regional level, each self-advocate on the Klippan national board has his/her own support person. At the national level, formal meetings almost always involve extensive decision making and as a result, the pairing of individual self-advocates and supporters creates a more personalised environment in terms of support, where self-advocates work closely with support staff to jointly prepare the issues for meeting agendas. The support person's role is to ensure the self-advocates understand the process and, when necessary, provide time for further consideration — by displaying red card — if the self-advocate does not understand. Moreover, at the national level, issues for discussion at meetings are often more complex, which sometimes leaves self-advocates dealing with "issues that they [the others in FUB-national executive]" would be better equipped to deal with, "such as prenatal diagnosis and the like, and what do you do then, when you are sitting there?" In these situations, support staff must be aware when help is needed.

Grunden National interprets the role of the coach in quite a different way than the local self-advocacy groups. The overarching idea among members of Grunden National is that coaches and self-advocates are more or less the same; that they are associates and their roles are interchangeable. One self-advocate in Grunden National explained that self-advocates did not immediately go to coaches when they needed support. Sometimes they approached another self-advocate for support instead. The same self-advocate also explained how the coach often turned to the self-advocates for advice: "He then of course turns to us.... that's why we call ourselves associates. We all help each other". Indeed, the coaches were sometimes portrayed by self-advocates as receivers of support. One self-advocate declared that, "I coach a lot
when it comes to calling officials when he (the coach) does not dare ... because I dare to make people in authority shaky". Another self-advocate stated of her coach that "he looks at me as if I am more of a coach to him. It is I who makes sure he eats lunch, otherwise he sometimes forgets". However, the same informant acknowledged that she requires support from her coach with her finances and relies heavily on his formal expertise.

Standby

A prominent theme in all Grunden self-advocacy groups at all levels is the expectation that support staff should be on "standby". That is to say, support staff should remain available, even when self-advocates are not exactly sure what kind of support they may require. Having coaches on standby as it were, is good:

Because then you can consult them if you like ... if there is no money or... with exchange of coins or something else. Then you have someone to turn to so it should not go wrong ... or if you need any help or so. Then simply: "Fetch the coach" if there is something you can't answer ... when we are having a barbecue afternoon, they are of course there and help us with the planning ... or just floating around, taking pictures or serving the food.

In Grunden National, a similar expectation is placed upon the coach to be available when needed: "It is up to us that work here to decide whether we need him [the coach] or not for a full day. The main thing is that he is around". Coaches on standby then, are always there at the self-advocates' disposal. In Klippan, however, the stand by phenomenon is most frequently expressed only at the local level of the organisation, and it is usually expressed by self-advocates as a wish for more frequent contact with a support person, preferably without having to share that support person with another peer.

To be on standby then, is a major expectation of all support staff in both the Klippan and Grunden organizations, although this expectation is more pronounced in Grunden. In Grunden, it is also possible to interpret the notion of "standby" as more than just a wish to increase the frequency of encounters with support staff, but also as an expression of who should have control of the resources. This is most clearly expressed in the claim of the Grunden self-advocates to determine the nature of their support, even when their specific needs are not necessarily conceivable in advance.

Generally speaking, the nature of the support for Klippan self-advocates is quite different to the support for Grunden self-advocates. There is, for instance, a uniformity to the support that Klippan self-advocates receive across all levels of their organisation. And this support conforms to a particular pattern, where support-staff, at all levels, tend to give structure to, and also lead, all self-advocacy meetings. By contrast, the nature of the support in Grunden self-advocacy groups is shaped by local issues and concerns that can extend to the other forms of employment some support staff are engaged in at any one time. Moreover, the Grunden model of self-advocacy, rooted as it is in an
egalitarian ideology that conceives of self-advocates and support staff as associates, prioritizes the idea of self-determination. In doing so, it sets the scene for tension and potential conflict within some self-advocacy groups around the issue of who should have the ultimate say within the group.

Initiative And Power

Power And Authority

Power is chiefly about control. It is about the imposition of the will of one actor upon another and it represents an asymmetric control over valued resources (Weber, 1964; Pfeffer & Salancik, 1978; Engelstad, 2006; Lukes, 2005). Power is also a relational and situational concept and it is ever present in all relationships (Parsons, 1963). As such, power represents a capacity to wield influence that may or may not be realized through the compliance of the other actors involved. (Anderson & Brion, 2014).

In organizations like Klippan and Grunden, the power dynamic between staff and self-advocates is difficult to analyze. Yet essentially it can be said that whoever controls the collective resources, wields the power and all power is chiefly based on some sense of formal authority (Ahrne 1994). Weber (1964) outlined three "ideal" types power. These three types, according to Weber, are legal or bureaucratic authority, based on formal statutory rules and regulations; traditional authority, based on a respect for customs, history and traditions; and finally charismatic authority, which is based on devotion to a leader and his/her personal charisma. In all three types of authority, participants accept authority and thereby offer their subordination voluntarily. Even in their obedience then, those people submitting to these types of "ideal" authority still maintain their freedom (Arendt, 2004). Etzioni (1964) adds a fourth type of power: professional power, which, he argues, is based primarily on exclusive formal knowledge of an organization. Professional power comes from understanding the central networks within the organization, and also from the vital relationships with key persons outside the organization. These networks and relationships are vital because they can fill gaps or structural holes in an otherwise sparse organizational network (Burt, 1992; 2004). Exclusive organizational knowledge then, is not unlike social capital, in that it gives the holder of such knowledge a position of authority.

These four sources of "ideal" power described above (cf. Anderson & Blon 2014) are, of course, practically inseparable. However, as analytical tools they can facilitate greater exploration. For the purpose of our own analysis of power in the Klippan and Grunden self-advocacy organizations, two categories of analysis – legal and other forms of power – have been used.

Legal Authority

Although the statutes underpinning the Klippan self-advocacy organization make no explicit reference to if, or when, staff should oversee group meetings, support staff tend to preside over all formal meetings and informal gatherings. Of course, some limited board positions exist for people with intellectual disability throughout the
Klippan organization, but even these positions of authority are usually subordinate to the support staff. Thus, self-advocates usually take on the role of "deputy," as illustrated by example of self-advocate J. in the following field note passage from one group meeting: "Except for L. [supporter], only J. raises questions or proposes new issues. The others just do so when being directed to by L. who otherwise strives to ensure that everyone should be heard".

In Grunden, each board possesses legal authority that is based not only on the overarching ideology of the organization, but also on the written statutes that define how the organization should operate. Positions on the Grunden boards are not tokenistic. Rather, they are positions of real power and are crucial to the day to day operation of each individual self-advocacy group. One chairman highlighted the way in which members on his board usually took the initiative and were constantly proposing the content of agendas for the Grunden meetings and summits in his organisation. He said, "We are the ones writing the agenda. What we should do or what issues come up. Thereafter, we leave it to them [other board members]". Economic concerns are a recurring theme in many organisations and most members are aware that they jointly shoulder an overall responsibility for their self-advocacy group. One board member explained how financial concerns were never far from the surface in his organization and highlighted the need for support in ensuring the group remained a viable operation:

"It's not easy to decide, that's why coaches sometimes must check that it does not go straight to hell .... that it has to do with money ... we do have limited financial resources."

Thus, the domain of decisions in Grunden sometimes extends to matters where the outcome of a decision might challenge the very existence of the organization if no, or the wrong, decisions are made.

If the domain for decision making is broader in Grunden than in Klippan, both organizations nevertheless have to ensure that self-advocates fully understand what they are deciding upon. At the regional and national level – in Klippan in particular – this dilemma is further complicated by the rising complexity of the issues at hand, which can range from matters of policy and strategy, to broader ethical concerns. To handle this rising complexity, more support-persons are present at the Klippan executive level meetings. Both the Klippan and Grunden self-advocacy organizations strive for consensus in their decision-making processes. In Klippan, for instance, voting procedures are rarely applied. One self-advocate explained, "we have tried that but the members think it is too messy". In Grunden, the custom is much the same. Self-advocates first work to achieve compromise or consensus and, only when that fails, will a decision go to a vote.

In Klippan, at the national level, a working committee prepares all issues for the meeting agenda. Self-advocates in Klippan are expected to speak up if they encounter problems grasping the pertinent issues, yet many tend to expect support staff to notice if a self-advocate is struggling to keep up. When these problems arise in Klippan meetings, they are resolved by certain formal procedures. For instance, when self-advocates do not understand a certain issue, they signal their
incomprehension by raising a red card. This brings a halt to proceedings – usually a two-minute break – in which the support person seeks to further explain the issue to the self-advocate who raised the red card. Only when a self-advocate raises a green card, to signal comprehension, may the meeting proceed. There are no such procedures governing Grunden self-advocacy meetings. Rather, self-advocates are supposed raise their own concerns when they encounter any difficulties. This is usually achieved when a self-advocate raises his/her voice and demands that their associates (peers or coaches) clarify the issue at stake. This procedure does not always work perfectly. In fact, some informants stated that they would rather refrain from asking questions, or remain silent, than appear less intelligent than their associates. Others admitted that sometimes they would not even be able to formulate the right questions to address the problem at hand. "I get the feeling that it would be wrong to ask that question," explained one self-advocate. "How should I explain it and how to make the other people understand what I mean?"

Other Forms Of Authority

Klippan support staff may lack legal authority in the sense that their role is not properly defined in either the statutes of the organization, nor in the broader FUB guidelines around effective support. Even so, their position of power rests in their exclusive knowledge of the Klippan organization. Furthermore, this power is enhanced by their solid social capital, which is in turn supplemented by a strong element of traditional authority and, in some cases even charismatic authority. Ultimately, this combination gives many Klippan support staff a superiority that few Klippan self-advocates could ever match. Furthermore support staff are also boundary-spanners in their organizational networks. That is to say, these staff occupy a central position in the broader organizational network by way of their relationships with municipal staff or the staff of other external bodies. One field note highlighted this issue:

One self-advocate wants to know whether B. [supervisor] has checked up the public meeting that he would like to attend [with the municipality]. "I love meetings" he asserts. B. promises to do that, but adds that even if you like to attend meetings no one has the time to do that every day of the week (Field notes).

The supervisor in this observation is considered a boundary spanner because he acts as a bridge between the organization and its environment, amid also because he interprets the appropriate norms of life outside the organization.

Only a handful of current Klippan self-advocates were involved in the foundation of the Klippan self-advocacy organisation. One informant explained how she and a few of her companions had been with the organization since its inception, but her story lacked any trace of mythological embeddedness or reference to tradition. "It was me and B. and A-L and K. from the beginning. Since then it (Klippan) has been filled up, little by little", she said. By contrast, a significant number of Grunden participants happily recalled the foundation of their organisation and, more often than not, they highlighted their own role in
the establishment of the Grunden self-advocacy network. One self-advocate recalled that: "the girls had a girl band ... And then we had a boy group. And then we said, let's merge the two into one organization". Many of these founding members still play an active role in Grunden and for that reason they possess a strong sense of legitimacy within the organization.

Assessing the extent of power that has its roots in exclusive knowledge is no easy task and the mere absence of formal boards in the local Klippan self-advocacy groups does not necessarily mean that knowledge of, and interest in public affairs, is a less prominent issue in the Klippan model of self-advocacy. In fact, in most local Klippan self-advocacy groups, there is usually a core group of self-advocates who have acquired a lot of control, who work alongside the support staff and act as representatives of their organisation. These more prominent self-advocates are often "deputized" by the support staff or elected by their peers to act as representatives on other boards inside and outside the organization. For instance, Klippan self-advocates have occupied positions on boards of the local Swedish Disability Federation, the FUB and also on boards of the regional or national Klippan assemblies. However, the support staff assume the responsibility for managing these situations and they also remain the key point of reference for all external contacts. Thus, the opportunity for such self-advocates to obtain a broad enough knowledge of their organization, and of the outside world, is limited by the nature of the support they receive. As a result, the opportunity to gain professional, knowledge based authority is further diminished.

There are charismatic self-advocates in several Grunden self-advocacy groups, some of whom have been members of the Grunden organization from the beginning. These self-advocates are usually well versed in local issues and besides occupying positions on the local boards, they have also developed other interpersonal skills over time, a direct result of the division of labour within the organization. Some self-advocates, for example, undertake work on newspapers and have contacts in external media organizations, others provide information about intellectual disability in schools and elsewhere. The development of such interpersonal skills creates avenues for Grunden self-advocates to amass a certain amount of social capital that would never be available to their Klippan counterparts. Indeed, some Grunden members occupy a central position within their organizational network and have direct access to municipal decision-makers, as illustrated by one coach, who spoke about the chairman of a local Grunden self-advocacy group as follows: "All the Town Hall knows A. A large part of the [municipality] knows A. and A. knows everybody". Some of these self-advocates also hold a formal position within their local self-advocacy group, and therefore have a strong voice inside and outside the organization. Of course, the distribution of the power-sources varies quite considerably across every Grunden self-advocacy group, but many self-advocates maintain a broad palette of authority, which often puts them on an equal footing with the coaches ostensibly employed to support them. Finally, this broad palette of authority is further reinforced by the legal authority self-advocates wield, an
authority that has been written into the statutes of the Grunden self-advocacy organization.

If most power sources are accessible to both self-advocates and coaches in the Grunden model of self-advocacy, in the Klippian model, the support staff have access to the widest range of power sources (except legal authority). As such, it is the support staff who ultimately maintain the most powerful positions in all levels of the Klippian self-advocacy organization. The Klippian self-advocates, on the other hand, with the possible exception of some charismatic self-advocates or "deputies," have very little access to the power sources outlined above. This explains their relative subordination within the organization, and also why the order of things is rarely challenged. It is therefore logical that our research uncovered no lasting conflicts between support staff and self-advocates in Klippian.

Given that Grunden self-advocates score highly on all four authority items, such a harmonious relationship could hardly be expected within the Grunden model of self-advocacy. As outlined above, several self-advocates were involved in the foundation of the Grunden self-advocacy organization and many were familiar with the local political situation. Others still, were charismatic leaders, occupied positions on the board or had acquired numerous skills as a result of the internal division of labor within the organization. Meanwhile, the legal authority of Grunden support staff was diminished by the very fact that coaches were denied any formal position on the governing boards. In contrast to the relative serenity that characterizes the Klippian self-advocacy organization, such conditions create a latent tension between support staff and self-advocates, which in some cases manifests itself in open conflict.

**Member Control And The Consequences For Self-Advocates**

Rules and norms serve as one of the most important mechanisms of coordination within an organization (Scott, 2003). In order to ensure that members act in accordance with an organization's expectations, whether these are codified in rules and statutes, or institutionally grounded, all organizations, including self-organized organizations, must have a system of control. They must also have consequences, or sanctions, for those who refuse to comply with those rules (Ahme, 1994). Rules usually become most apparent when they are broken, and the most drastic sanctions in both the Klippian and Grunden self-advocacy organizations are exclusion, and in the most extreme cases, expulsion.

**Control Of The Members**

Control or governance can take a number of different guises. Perrow (1979), for instance, outlines three different forms of control: direct control, bureaucratic control and discreet control. Direct control is generally exerted by step-by-step procedures and maintained by overt monitoring to ensure compliance. By contrast, bureaucratic control is more discrete because the underlying premise is that the measures for control – rules, procedures, appropriate forms of communication – are embedded in the structure of the organization. Simon (1957) describes the extent of control of an organization over its members lives as the
zone of acceptance (Simon, 1957). The marine corps, as Simon points out, exemplifies an organization with a wide zone of acceptance, while schools that provide only evening classes would be described as having a more restricted zone of acceptance. Wider zones of acceptance facilitate more complex forms of control. The concept of the zone of acceptance is a useful analytical tool to form an approximate measure of an organization's potential influence over the lives of its members.

Which forms of control are the most dominant in the two organizations analyzed for this study? Direct control can only be applied from a position of authority and the only people with that sort of legitimate authority in Klippan and Grunden are support staff or the board members, vis-à-vis their fellow self-advocates. And while self-advocates who are board members of their respective self-advocacy organizations might be described as devoted, the data indicates that they do not monitor their colleagues or the organization's activities to any great extent. As for support staff, the picture is more complex. As shown above, there are examples where supervisors in Klippan exercise direct control by adjusting some "incorrect decisions" taken by self-advocates, though this does not occur frequently. Klippan supervisors also prepare the agendas for meetings, formulate proposals for decisions in matters where such shall be taken, and clarify messages when discussions arise. This is a discrete form of control, rooted in a common ideological background. However, if there are no other involvements than self-advocate's local membership, these incursions amount to a limited number of hours per month, which therefore hinders any continuous control outside of the meetings. The zone of acceptance is therefore quite narrow in Klippan.

In Grunden, in many cases support staff divide their time between working as coaches in the local self-advocacy organizations and in employment in other local disability services. The data do not clearly indicate the extent of control a coach in any one organization might wield, but no self-advocate who had a position on a Grunden board claimed that support staff exerted direct control over their organization's daily activities. However, there were some instances of coaches engaging in a direct form of control over some participants in some local working groups.

As public organizations ratified by law, Grunden self-advocacy groups are subject to bureaucratic control through compulsory audits and annual reports. It is possible to conceive of this as a discrete form of control, because of the articulated ideology and the basic values underpinning the Grunden organization. However, it is doubtful that this form of control is maintained by overt monitoring, because participants adhere to, and believe in the organization's objectives and goals. It is plausible that coaches are more informed about the everyday life of the Grunden self-advocates than their counterparts in Klippan. These long exposure times and the relatively good relationships with local municipalities indicate that there is a wider zone of acceptance in Grunden than there is in Klippan.
Consequences

As we have already noted above, the Klippan self-advocacy organization has no written rules governing the day to day operations of its organization. Even in the FUB-designed statutes for regional or local Klippan groups, there is no mention of how or why a member might be excluded or expelled from the Klippan organization. Thus, it is hardly surprising that there are no clear procedures outlined that govern the way in which members might be expelled for transgressions. It is worth noting however, that the statutes for the FUB-local organizations do permit expulsion of any self-advocate who deviates from the established objectives or policies of the organization. Yet no such exclusion has taken place (Oral Communication, 20150903).

In our interviews with Klippan members, none could outline the rules that governed their local self-advocacy group. However, this does not mean that any sort of behaviour was tolerated by the group. As noted already, there are a number of standards such as "showing each other respect... not saying mean things to each other" that are cherished as behavioural norms within the organisation. These norms extended to helping each other, to ensuring that members listened to one another and did not interrupt other members when they were talking.

Meanwhile, in some Klippan self-advocacy groups, drinking alcohol is prohibited, a behavioural norm that lacks any equivalence within the Grunden organization. It is up to the supervisors to maintain all these rules and codes of behaviour, though not all Klippan members are happy submitting to the rules. One informant expressed his disappointment with the no alcohol rule as follows: "when we ... go away somewhere... then it sometimes would be nice just to take glass of wine. But we are not allowed to. And that makes us feel like a little down ... because naturally we can take care of ourselves."

The statutes governing Grunden National clearly outline two reasons for which a member might be expelled. First, a member can be expelled for working against the organization's objectives, though no one has ever been expelled for having done so. Second, a member might be expelled for not paying membership fees and quite a few have been expelled for failing to comply with this rule. At a local level however, Grunden self-advocacy groups are similar to their Klippan counterparts in that they have no clearly defined standards of behaviour. There was only one group that had written rules of conduct, and in that case the expected norms were not dissimilar to Klippan expectations. That is to say, behavioural codes revolved around prohibiting violence, sexual harassment, and the use of abusive language. In this case however, the rules also stipulated that a self-advocate who came across such behaviour was expected to bring this to the attention of the board.

Similar reasoning occurred in another Grunden self-advocacy group where, despite the absence of written rules, some far-reaching sanctions were applied against people who behaved inappropriately or violated important standards. One chairman outlined how one of her colleagues, who harassed her over the telephone, received such a sanction:
Then I made contact with the coach X... And then they (the coaches) had a conversation with this guy... And he was warned a couple, three, times. We had meetings with him and also explained. Then he promised on his honour that he would end calls and harassments, hanging up and yelling and screaming in the phone, whatever it was. And then the coaches had a meeting with him and they phoned him. 

(However) he went on, so after a while we – me and the vice-chairman – jointly decided to address it at next meeting. Today that person is no longer around because of what happened.

Although similar behavioral codes are cherished by both the Klippan and Grunden organizations, each organization resorts to different methods of control to ensure that such behavioral codes are upheld. In Klippan, the supervisors exert a more direct control through their pro-active forming of the agenda and governance of meetings and this is combined with the indirect control, which is embedded in supervisors’ common role. In Grunden an unobtrusive control prevails but it has its roots in an active and shared identification with the organization’s overarching ideology. More interestingly however, is the bureaucratic control Grunden must rely upon because it remains an organization heavily dependent on its organizational field. As each Grunden self-advocacy group is an individual and formal entity, it must draw up financial statements and annual reports. And doing this requires resources and extensive control. Moreover, the way in which Grunden deals with transgressions of its rules also illustrates the organization’s environmental dependency. To retain its legitimacy in the eyes of those responsible for the funding of Grunden self-advocacy, it would have been impossible for Grunden to let a violation such as the abovementioned harassment case slide, because Grunden’s ideological commitment is that all people are of equal value. The responsibility of handling transgressions lies with the self-advocates, most notably the members of the board, though coaches might also have to play a role. By contrast, in Klippan a greater reliance exists on supervisors to directly curb undesirable behavior. As such, it is much less likely for an abusive situation to occur like the Grunden one described above. And it stands to reason that no expulsion on such grounds would occur.

Finally, it is worth noting that the ideology of Grunden underlines the similarities between people with intellectual disability and other people. As such, the right to consume alcohol and attend an evening at a bar or pub is understood as a natural form of encounter. By contrast, the direct control in Klippan facilitates a prohibitive approach to alcohol consumption, which was something some self-advocates found paternalistic and a shame.

Discussion

The Klippan model of self-advocacy is fundamentally geared towards leisure time activities, which means that by its very nature, it has a narrow zone of acceptance and only offers a limited time for interaction – at most a few hours a week – to its members. On the other hand, the less structured Grunden model of self-advocacy has a wider zone of acceptance, primarily because it facilitates extensive
(sometimes whole-day) interactions among its members. Although no signs of greedy organizations (Coser, 1974) were detected – for instance the Grunden organization did not incrementally raise its demands on the loyalty of its members to the organization – the expectations on members of Grunden were certainly greater than on members of Klippan.

The higher frequency of interaction among self-advocates in Grunden might partly explain the increased sense of responsibility some Grunden self-advocates felt for their organization. It might also partly explain their diligence in maintaining greater regulation of the system governing behavioral norms. However, we assert that the most important key to understanding the differences between the Grunden and Klippan models of self-advocacy, lies in their somewhat different organizational fields (for a brief characterization, see table 2 below). Grunden National and the local Grunden self-advocacy groups are all autonomous organizations and they primarily draw their legitimacy and resources from other organizations and from the general public. This is a fundamental aspect of Grunden that demarcates it from Klippan, and also explains the variation in the other categories for analysis we have elaborated on above, such as issues of power, the role of support staff, control and its consequences. To a lesser extent, this fundamental aspect of Grunden can also explain the subtler differences between Grunden and Klippan in terms of affinity and expectations.

Table 2 (below) provides a comparison between the fundamental organizational characteristics of the Klippan and Grunden self-advocacy organizations. They key categories of analysis in this table are as follows: Organizational Field, Affinity, Expectations, Support Staff, Power and Control/Sanctions.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Klippan</th>
<th>Grunden</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Organizational field (OF)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relations to OF</td>
<td>Relatively few</td>
<td>Many relations</td>
<td>Extensive</td>
</tr>
<tr>
<td>Dependency on OF</td>
<td>Weak excluding FUB</td>
<td>Strong</td>
<td></td>
</tr>
<tr>
<td>General character of OF</td>
<td>Stable &amp; Homogeneous</td>
<td>Turbulent &amp; Heterogenic</td>
<td></td>
</tr>
<tr>
<td><strong>Affinity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Membership</td>
<td>PWID (within FUB)</td>
<td>PWID &quot;so called&quot; Intellectual Disability</td>
<td></td>
</tr>
<tr>
<td>Entitled to represent</td>
<td>PWID</td>
<td>PWID (excluding treasurer/secretary)</td>
<td>Limited</td>
</tr>
<tr>
<td>Speaking for</td>
<td>PWID</td>
<td>PWID-&gt; All people with disabilities</td>
<td></td>
</tr>
<tr>
<td>Recruitment</td>
<td>Limited</td>
<td>Actively/Continuously</td>
<td></td>
</tr>
<tr>
<td><strong>Expectations</strong></td>
<td></td>
<td></td>
<td>Limited</td>
</tr>
<tr>
<td>Characteristics</td>
<td>Klippan</td>
<td>Grunden</td>
<td>Difference</td>
</tr>
<tr>
<td>-----------------------</td>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Goals/Purpose</td>
<td>Participate in society &amp; good living conditions for PWID &amp; their families</td>
<td>The same excl. &quot;family&quot; + stressing independence &amp; recognition</td>
<td></td>
</tr>
<tr>
<td>Activities</td>
<td>Social activities, study circles, Political work</td>
<td>The same + board meetings &amp; political activism locally.</td>
<td></td>
</tr>
<tr>
<td>Rules/Conduct codes</td>
<td>Similar</td>
<td>Similar</td>
<td></td>
</tr>
<tr>
<td>Support Persons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Background</td>
<td>Internally (FUB) recruited</td>
<td>Heterogenic group.</td>
<td></td>
</tr>
<tr>
<td>Role content</td>
<td>Uniform nationwide</td>
<td>Locally negotiated</td>
<td></td>
</tr>
<tr>
<td>Role in board</td>
<td>Form the agenda, Chair the meetings</td>
<td>Excluded from board Chairman &amp; board members form the agenda</td>
<td>Extensive</td>
</tr>
<tr>
<td>Position</td>
<td>Vital, Boundary spanner</td>
<td>Associate, Stand by</td>
<td></td>
</tr>
<tr>
<td>Conflicts with self-advocates</td>
<td>Small conflicts</td>
<td>Reoccurring conflicts, passivity risk (silence)</td>
<td></td>
</tr>
<tr>
<td>Power</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Board</td>
<td>Often no board</td>
<td>Only self-advocates</td>
<td></td>
</tr>
<tr>
<td>Positions</td>
<td>No positions excl. &quot;deputies&quot;</td>
<td>Positions vital</td>
<td></td>
</tr>
<tr>
<td>Ec. accountability</td>
<td>No economic accountability</td>
<td>Economic accountability</td>
<td>Extensive</td>
</tr>
<tr>
<td>Domain of decisions</td>
<td>Small domain of decisions</td>
<td>Wide domain including funding/survival issues.</td>
<td></td>
</tr>
<tr>
<td>Board members' power sources</td>
<td>Limited (e.g. charisma) or no authority</td>
<td>Some authority based on legality, tradition, charisma, skills or network position</td>
<td></td>
</tr>
<tr>
<td>Voting procedure</td>
<td>Few voting procedures</td>
<td>Consensus, eventually voting</td>
<td></td>
</tr>
<tr>
<td>Control &amp; Sanctions</td>
<td></td>
<td></td>
<td>Extensive when occurring</td>
</tr>
<tr>
<td>Rules</td>
<td>Few rules</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characteristics</td>
<td>Klippan</td>
<td>Grunden</td>
<td>Difference</td>
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<td>-----------------</td>
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<td>-------------------------------------</td>
</tr>
<tr>
<td>Forms of control</td>
<td>Direct control + indirect</td>
<td>Indirect/unobtrusive + bureaucratic</td>
<td></td>
</tr>
<tr>
<td>Controller</td>
<td>Supervisor</td>
<td>Chairman/board</td>
<td></td>
</tr>
<tr>
<td>Sanctions</td>
<td>No expulsions</td>
<td>If necessary: expulsions</td>
<td></td>
</tr>
</tbody>
</table>

In Grunden, legitimacy extends to living up to the image of being governed by the self-advocates themselves. For example, the board must exhibit a capacity to deal appropriately with misconduct by members when basic and ideological values are seen to be at risk, even when the statutes give no guidance as to what action should be taken. In other words, legitimacy will extract organizational control as well as a capacity to implement sanctions for transgressions that might tarnish the reputation of the organization. Furthermore, the right to self-determination is one of the central ideological pillars of Grunden's philosophy. To remain credible then, Grunden must practice what it preaches and this extends to instances where legitimacy demands that the coaches' power be constrained to ensure they do not exert undue influence over the organizations' decisions.

Organizational field orientation theory also explains, to some extent, why supervisors in Klippan retain more direct control over, and provide more uniform support to, the self-advocates in local Klippan self-advocacy groups. Furthermore, the environmental dependency of Grunden helps us understand the organization's approach to enforcing penalties such as expulsion. An organization that allows bullying or abuse could never be a credible representative for any oppressed groups. In the long run, such an organization would not only face a crisis of credibility. It would also have to contend with shrinking resources and decreased interest from its external partners. This becomes especially important in terms of relationships with municipalities, which provide most of the resources for support staff, other operating grants, and also the funding for most of the groups' facilities. Centralized funding from the State also favors organizations that are sufficiently large and preferably growing. Thus, there is an incentive for Grunden to encourage the establishment of new local self-advocacy groups and the recruitment of new members.

Klippan, connected as it is to an established institution in disability politics (the FUB), does not have to contend with issues of legitimacy. In fact, the ongoing issues of legitimacy that threaten to undermine the Grunden self-advocacy movement on a regular basis are virtually nonexistent in the Klippan self-advocacy movement. Nor does Klippan need to contend with the equally important issue of a scarcity of resources, because resources are generally quite secure and accessible from a stable funding source. This means that local boards with responsibility for finance and other coordination issues are not required. This, of course, also means that the decision domain of Klippan is restricted to social, rather than organizational issues. As Grunden self-advocates spend considerable time working to ensure their organization's continued existence, Klippan self-advocates spend more time organizing leisure activities, such as possible destinations for group trips, the literature for their reading circles or the restaurants they intend to visit. Similarly,
the recruitment of new members is not a high priority for the Klippan organization because it will be weighed against the ongoing shortage of, and difficulties in, recruiting new support staff.

In terms of the expectation and affinity categories of analysis, these reveal slight but important differences between the Klippan and Grunden models of self-advocacy. The norms and codes of behavior are quite similar in each organization, except for the fact that some "adult" activities are prohibited in Klippan and there is a higher expectation on Grunden self-advocates to engage in activism. The main difference in affinity is how the target group is defined by each organization and Grunden's occasional claim to represent a wider group of people with disabilities than just those with intellectual disability. This claim might be explained by the considerable effort Grunden has made to obtain national recognition.

Generally it seems that the main differences between the Klippan and Grunden organizations can be attributed to their quite different organizational environments. Moreover, it is hard to ignore the way in which the Grunden model of self-advocacy shares some similarities with Goodley's ideal model of self-advocacy (2000). For one thing, Grunden self-advocacy groups are autonomous organizations and independent from professional services and parental bodies. And Grunden certainly shares another feature Goodley's model in that the organization is constantly challenged by a shortage of resources. Yet even in terms of its funding, the picture is not quite so clear cut. Grunden self-advocacy groups are financially independent from other service providers only in the sense that coaches do not have a day-to-day impact on the organizations. Indeed, when it comes to funding, the local self-advocacy groups remain heavily dependent on transmitted resources and receive operating grants from Day Programs for people with intellectual disability and from other municipal authorities. Meanwhile, in almost all cases the coaches were connected to the municipality service system, which meant that they might hold a potential conflict of interest. However, as noted, this financial dependency does not lay restrictions on the self-advocates' will to express their views about the professionals employed to support them, nor about their relationships with external organizations.

The similarities between Goodley's (2000) divisional model and Klippan are even more obvious. The operational resources are more readily available and supervisors seem well equipped to handle most advocacy measures. Also, the data presented here gives concrete examples of the way in which some self-advocates were in fact "overpowered and relegated to the back seat" (ibid.) within their own organization. Curiously though, no obvious potential conflicts of interest for support staff were detected, although it would be possible to interpret the restrictions on alcohol, the recurrent patterns of diet recommendations, and tendency of parents to pick up self-advocates before meetings had finished, as a conflict of interest.

**Conclusion**

It is worth noting that this article is only concerned with the two most prominent self-advocacy organizations for people with intellectual disability in Sweden. The aim of this article was to explore and understand the similarities, and especially the differences, between the Klippan and Grunden models of self-advocacy. From the analysis so far, one might conclude that the Klippan model is a more introverted model than that of Grunden. And given that one central point of the self-advocacy movement is engendering the empowerment of people with intellectual disability, it
might, at first glance, also seem as if the Klippan model of self-advocacy is redundant or even counter-productive. However, this conclusion would only hold if the local level of the organization were the exclusive focus of any analysis. But the Klippan self-advocacy organization is best understood through an analysis across all levels of its organization. This is because the socio-political mobilization efforts in Klippan are essentially managed at the executive level. This mobilization is, of course, achieved through regular meetings between the national board of the FUB and the Klippan central committee. It is here, at the executive level, that resources are allocated to wield influence in debates in disability politics, for lobbying, for maintaining the function of the committee as a consultative body vis-à-vis the central authorities, and for forming collaborations with other organizations to safeguard common interests. A common trait that Klippan shares with Grunden then, is a division of labor. In Grunden the division of labor occurs in each individual self-advocacy group. In Klippan, by contrast, the division of labor occurs across the entire Klippan organization. The local Klippan self-advocacy groups might well be described as essentially introverted organizations. But they can afford to be, because their national committee is explicitly extroverted (or political) and constantly lobbying for social change.

In order to survive, every organization must acquire legitimacy and power, as well as resources from its environment (Pfeffer & Salancik, 1978; Hall, 1991). The local environment and described order is easily understood where the local self-advocacy groups only exist in small municipalities with a limited number of active self-advocates. However, at least in some local groups, political mobilisation in the sense that a more active political influence is sought, is also a prominent feature. When someone, notably the Klippan supervisors, have direct contact with the municipality (e.g. having seats in the municipal boards or equivalent) or with the disability councils and other local authority bodies this also makes a difference. In conclusion it seems difficult to assert that the collective aspect of empowerment in self-advocacy is not present, although this more hierarchal order in Klippan problematizes the individual potential to empowerment.

Introversion is also a feature of the Grunden self-advocacy model but it is usually subordinate to stronger, extroverted forces within the organization. By arranging national and regional workshops, by taking part in national research groups, and by striving for seats on national disability boards, Grunden National attempts to play a role in shaping Swedish disability policy. And all of this is complemented by proactive, though less coordinated local policies in the municipalities. The boundary-spanners here are mostly the chairman, or other formal board representatives, who have established their own direct links to local politicians and policy makers. The main point is that in Grunden, survival requirements propel and sustain a network of contacts at a local level. That is to say, the Grunden self-advocacy groups are forced to act as outward facing organizations at a national level but even more so at a local level. This process of network building and maintenance is the key to Grunden's success but also what places the organization in jeopardy. In other words, it is a precarious model where its strength is also its Achilles-heel because if the model fails the organization may cease to exist.

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Return to Top of Page

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