

Diversity and Divisions in the Swedish Disability Movement: Disability, Gender, and Social Justice

AGNETA HUGEMARK* & CHRISTINE ROMAN**

*Department of Sociology, Uppsala University, Sweden, **Social and Political Sciences, Örebro University, Sweden

ABSTRACT *There is lively discussion in the social sciences about minority groups and their claims for social justice. Universalism versus difference and redistribution versus recognition are two important issues of debate. This paper takes a closer look at the social justice claims articulated by the Swedish disability movement. It discusses how questions of representation, collective identity, and needs interpretations are dealt with in a number of disability associations. One important assumption guiding our study is that the interpretations of members' needs, how their needs can best be met, and who is to have the legitimate right to communicate their needs, are questions subject to constant debate. The aim is to demonstrate some of the complexities confronting the disability movement in its struggle for social justice. To be more specific, we set out to show two things: (i) how different kinds of justice claims are balanced by the investigated organizations; and (ii) that the demands for cultural recognition and socioeconomic redistribution are raised not only by the disability movement vis-à-vis the state, but also by groups within the disability movement vis-à-vis other groups in the movement.*

The Swedish disability movement is struggling to change perspectives on disability policy from being (solely) a matter of providing care, to one of democracy, citizenship and human rights. It has strongly emphasized that people with impairments have the right to participate fully in society and make decisions concerning their lives. In addition, it has been pointed out that people with impairments suffer not only from socioeconomic disadvantage, but also from having the experience of not being recognized in their own right. Like the “new social movements” that took shape in the 1960s and 1970s, the disability movement has emphasized that causes of injustices are embedded in unquestioned norms, habits and symbols, and has called attention to the fact that a universalistic welfare state policy may serve to suppress differences and establish as a norm the experiences and interpretations of dominant social groups. Accordingly, a discourse on a cultural politics of recognition has played an important role in the movement's

Correspondence: Agneta Hugemark, Department of Sociology, Uppsala University, Sweden. Email: Agneta.Hugemark@soc.uu.se

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struggle for social justice (see, for example, Barnes, Mercer & Shakespeare 1999, Barnes, Oliver & Barton 2002, Lister 1997).¹

This article takes a closer look at the social justice claims articulated by a number of Swedish disability organizations. Taking our point of departure in the theoretical discussion on the relationship between equality, difference and social justice (see below), we wish to illuminate how questions of representation, collective identities, and needs interpretations are dealt with in these organizations. We thereby hope to make an empirical contribution, if only a small one, to the often highly abstract discussion on social justice. One important assumption guiding our study is that the interpretation of members' needs, how their needs can best be met, and who is to have the legitimate right to communicate their needs, are questions subject to constant debate (Fraser 1989).

In the present article, we aim to demonstrate some of the complexities confronting the disability movement in its struggle for social justice. To be more specific, we set out to show: (i) how the different kinds of justice claims are balanced by the organizations in our study; and (ii) that the demands for cultural recognition and socioeconomic redistribution are raised not only by disability organizations vis-à-vis the state, but also by groups within the disability movement vis-à-vis other groups in the movement. We thus presume that people with impairments form a heterogeneous category. Firstly, it is heterogeneous in the sense that type and degree of impairment may affect group identities and needs interpretations, which in turn may affect political claim-making. Secondly, social divisions other than the non-disabled/disabled divide cut across the lives of impaired people in complicated ways. Feminist researchers have convincingly demonstrated that gender is one of the most important categories distributing privileges and shaping experiences. The intersection of disability with gender and other forms of oppression has thereby been placed on the theoretical agenda in disability studies (Barron 2004, Kristiansen & Traustadóttir 2004, Thomas 2002, Verner & Swain 2002). This question is also central to our analysis.

After these opening words, we briefly introduce a discussion on social justice that is ongoing in the social sciences. In particular we elaborate on Nancy Fraser's theory of social justice. The next section describes the procedure of our empirical work. Subsequently, we discuss the ways in which claims for redistribution and recognition are balanced in disability organizations. The two following sections examine ongoing struggles over resources and needs interpretations between and within organizations. After that, additional complexities are pointed out by way of an analysis of intersections between gender and disability. That is, this time the disability movement's struggle for social justice is investigated by taking our departure from another power structure. The final section contains some concluding remarks.

Equality, Difference and Social Justice

Different aspects of social justice have been much discussed during the past decades, i.e. that social justice is not exclusively a question of distribution of

material resources and social positions, but also a question of possibilities for social groups to articulate and communicate their own experiences and perspectives (Barnes, Mercer & Shakespeare 1999, Stuart 1996, Thomas 2002). Hence, equality involves not only rejection of irrelevant differences, but also full recognition of legitimate and relevant ones. Setting out from this assumption, universalistic welfare policy has been criticized for disregarding and suppressing the “difference” of minorities and subordinated groups (e.g. people with impairments, ethnic minorities, women), and for generalizing the experiences and culture of dominant groups (e.g. non-disabled people; ethnic majorities, men). While the expressions and identities of the latter groups are constructed as normality, the particular perspectives and experiences of the subordinated groups are devalued or rendered invisible (Fraser & Honneth, 2003, Taylor 1992, Young 1990).

Nancy Fraser’s explicit aim is to broaden the theory of social justice to encompass both the redistribution and recognition aspects of justice. The normative core of her concept is the notion of parity of participation, i.e. that it is not compatible with justice that some individuals are denied participation in social interaction on equal terms (Fraser 1997, 2000, 2001, 2003). On the one hand, the distribution of material resources must secure the independence of participants. This precludes forms and levels of material inequality and economic dependence that impede parity of participation (e.g. deprivation, exploitation, large differences in income and wealth). On the other hand, all participants must have the same possibilities to attain social esteem. This precludes institutionalized value patterns that deny some people the status of full partners in interaction, e.g. cultural domination, non-recognition and disrespect. Social justice requires instead that value patterns express equal respect for all participants and ensure equal opportunity for achieving social esteem (Fraser 2001:29). The different types of claims form two paradigms of social justice, one emphasizing the need for economic restructuring of the division of labour, property or income, and the other the need for cultural and symbolic change, such as the revaluation and preservation of difference. In addition, they approach group differences in different ways. While the redistribution paradigm assumes that it is classes or class-like collectivities that suffer from injustices and that group differences must be abolished, the recognition paradigm insists instead that the particularities of social groups must be recognized and revalued (Fraser 2003:11–16).

The different aspects of social justice may be treated as two distinct perspectives on social justice that can be applied to any social movement. Whether the dimension of redistribution or the dimension of recognition is predominant in a particular case is an empirical question (Fraser 2003:12). This perspectival dualism thus implies that redistribution and recognition do not correspond to two different substantial domains: economy or culture. They rather constitute two analytical perspectives that can be used to study each domain. Far from being mutually exclusive, claims for recognition and for redistribution tend to reinforce each other in a dialectical manner (Dahl 2004). Importantly, the normative concept of participatory parity is useful at both the intergroup and intragroup level. That is, it supplies the standard for

assessing both “the effects of institutionalized patterns of cultural value on the relative standing of minority groups vis-à-vis majorities” and “the internal effects of minority practices” (Fraser 2003:40).

In line with Fraser’s argument, and research within disability studies (e.g. Ferguson 2003, Thomas 2002), we assume that people with impairments may suffer from both injustices rooted in culture and injustices rooted in the political economy. Thus, like the feminist movement, the disability movement must claim the redistribution of economic resources, as well as the recognition of group experiences and the revaluing of disrespected identities. Such claims stand in an uneasy relation to each other, however. Whereas claims for recognition tend to promote group differentiation, the politics of redistribution aims at abolishing the kinds of economic institutions and arrangements that support group differences (Fraser 1997, 2003). This dilemma is designated by Fraser as the redistribution-recognition dilemma. It has been much discussed within feminism in terms of equality and difference (Echols 1983, Nicholson 1990, Minow 1991, Rhode 1990). We assume that the disability movement, like the feminist movement, to some extent faces a contradictory task when framing and articulating claims for social justice. It must address conflicts arising from needs for economic redistribution, on the one hand, and needs to be recognized as a social group with distinct experiences, on the other hand (Morris 1996). In the following sections, we will try to illuminate, step by step, how some actors in the Swedish disability movement handle the above-mentioned kinds of conflicts.

Methods

The present article is part of an ongoing research project that studies struggles for social justice in the disability movement. It is funded by the Swedish Council for Working Life and Social Research (FAS). In this article the term “disability movement” is used to mean disability organizations and thus approach the latter as carriers of the disability movement (Ahrne 1994:67–68). The empirical data analysed here are drawn from four individual-based organizations and two meta-organizations (i.e. organizations whose members are other organizations).

The sample of individual-based organizations includes The Swedish Association of the Visually Impaired (SRF, *Synskadades Riksförbund*), The Swedish National Association of the Deaf (SDR, *Sveriges Dövas Riksförbund*), The Swedish National Association for Persons with Intellectual Disability (FUB, *Föreningen för Utvecklingsstörda Barn, Ungdomar och Vuxna*), and The Swedish Federation of People with Mobility Impairments (DHR, *De Handikappades Riksförbund*).² Several considerations have guided this selection. The organizations chosen are relatively large and old, they have strong voices in public debates on disability; and they put different amount of weight on claims for redistribution and recognition, respectively.

The two meta-organizations are The Swedish Disability Federation (HSO, *Handikappförbundens samarbetsorganisation*) and Forum – Women and Disability in Sweden (*Forum – Kvinnor och handikapp*). The former was

chosen because it organizes the vast majority of individual-based disability organizations in Sweden.³ The choice of the latter organization was guided by our interest in intersections between disability and gender. It was originally established as the result of a perceived absence of a gender perspective within the disability movement.

One empirical data source used in this article is written documents, such as political programmes, regulations, reports from annual meetings, reports on gender equality projects and networks. Another source is interviews with key-people. We have conducted semi-structured interviews with 11 people who represent the six above-mentioned organizations, including presidents and people representing different division or networks within the organizations. The thematic interviews were structured around questions about the respective organization's activities, important political issues, economic resources, gender questions, rules for membership and representation, decision-making processes and cooperation with other disability organizations. The interviews lasted around 1 hour, were accurately and fully transcribed, and sent to the informants for approval. The concepts of needs interpretation, representation and collective identity have been central to our analysis.⁴ When translating quotations from Swedish to English, we have tried to convey the informants' specific messages, rather than translating verbatim. Quotations have also been edited slightly to enhance readability.

Balancing Redistribution and Recognition Claims

How do the different disability organizations in our study balance different social justice claims? Which societal changes are perceived as necessary in order to make parity of participation for their respective members possible? As will become clear, there are substantial differences between the organizations in these respects.

We mentioned above that the Swedish Disability Federation (HSO) is a meta-organization for the vast majority of individual-based disability organizations in Sweden. It puts much emphasis on equality and parity of participation. "The goal is a society for everyone that is characterized by solidarity, equality and participation" (www.hso.se). Respect for difference is seen to be at the very core of the organization's political work. In keeping with this, it is stressed that "people with impairments, and their needs" should be "considered as important as people without impairment and their needs" (www.hso.se).

We are working together . . . based on an assumption of the equal value of all human beings and the equal rights of all human beings. The equal value of all means respect for human life, notwithstanding our differences and different abilities. The equal rights of all, means the right to fully participate together with others in societal life (www.hso.se).

However, parity of participation requires more than merely respecting differences. According to The Swedish Disability Federation (HSO), redistribution of economic resources and organizational change are also of vital importance. It is asserted that the "basis for a successful disability politics" is

the existence of powerful laws in combination with universal welfare policies (www.hso.se).

Redistribution and recognition claims are also intertwined in the political programmes put forward by the individual-based disability organizations. Two of them: The Swedish Federation of People with Mobility Impairments (DHR) and the Swedish National Association for Persons with Intellectual Disability (FUB), seem to place more or less equal weight on both aspects of social justice. The ways in which the two types of social justice claims are balanced by The Swedish Association of the Visually Impaired (SRF) and The Swedish National Association of the Deaf (SDR) are, however, undoubtedly at variance (Hugemark & Roman 2005).

One of them, The Swedish Association of the Visually Impaired (SRF), places a great deal of emphasis on equality and redistribution of economic resources. The sameness of people with and without visual impairments is consistently stressed. “We are part of the public, even though we sometimes need special solutions in order to use a service or to participate on equal terms.” A politics of redistribution is considered absolutely necessary to make parity of participation possible for people with visual impairments. It is also underlined that the improvements already made are largely dependent on a universal type of welfare system.

A universal, tax funded welfare politics that is free from indiscrete and insulting means testing is the best way to meet our needs. Respect for the integrity of visually impaired people is best maintained by the means of universal measures (www.srfriks.org).

The problems and remedies that are identified by The Swedish National Association of the Deaf (SDR) are markedly different. Whereas the Swedish Association of the Visually Impaired (SRF) strongly emphasizes the need for a politics of redistribution, this organization above all describes injustices in terms of cultural devaluation. It establishes that “the greatest barrier” for deaf people is the ignorance and lack of understanding of their “particular culture, problems and needs”. It is also emphasized that sign language is the mother tongue of the deaf.

We don't look upon ourselves as disabled, but as a linguistic minority group.⁵ There are no barriers in the encounter between two signing persons. Barriers arise in the communication with the hearing society, which uses a language different from ours, a language that we cannot hear . . . (www.sdrf.se).

The Swedish National Association of the Deaf (SDR) understands the deaf culture as “the very nerve in the lives of deaf people”, and sign language is seen as a necessary precondition for the “deaf culture as a way of life”. In keeping with this, the struggle to strengthen this language, and to give it official status as a minority language, is an issue of great importance in SDR.

The above examples demonstrate significant differences between the kinds of social justice claims articulated by the organizations in this study. Whereas The Swedish Association of the Visually Impaired (SRF) places considerable weight on the need for economic change, The Swedish National Association

of the Deaf (SDR) emphasizes instead the importance of cultural change, i.e. revaluation and recognition. As we have pointed out earlier the different kinds of social justice claims are far from mutually exclusive, however. For example, the prominence given to redistribution by the former organization is accompanied by an insistence on the importance of recognizing group-specific experiences of people with visual impairments. Likewise, a redistribution of economic resources seems to be vital in order to provide, for example, the number of sign-language interpreters necessary for deaf people to participate equally in social life.

Old Versus New Organizations

Having discussed the ways in which disability organizations may balance social justice claims differently, we will now consider how group identities are constructed by the organizations in our study. Who are the “we” claiming social justice? What do “we” have in common? How are “we” differentiated from other social groups? The following discussion implies that there is no straightforward answer to these kinds of questions. The examination of the relation between The Swedish Disability Federation (HSO) and the individual-based organizations instead makes clear that different actors draw the dividing lines between groups of people differently. Besides a complex pattern of group difference, there is also a struggle going on between organizations over resources and needs interpretations.

The Swedish Disability Federation (HSO) presents itself as “the collective voice of the Swedish disability movement” (www.hso.se). To be more precise, this “collective voice” refers to people with “visible or invisible impairments” (HSO 2002).

The dichotomy between “us” and “them” is thus constructed by HSO as the difference between having and not having impairment. The representatives of the individual-based organizations that we have interviewed make additional distinctions, however. Categorizing their own respective organization as a classic and traditional kind of disability organization, they all in fact seem to draw a sharp line between “old disability organizations” and “new disability organizations”. In this way, our informants stressed that the organization they represent shares a common interest only with some of the member organizations of The Swedish Disability Federation (HSO).

One informant designated the old disability organizations as “access organizations” and the new ones as “patient organizations”. Although all informants did not use these exact terms, we will adopt them in the following paragraphs.⁶ In what respect, then, are so-called “patient organizations” seen as different from “access organizations”? Here, differences in members’ needs are mentioned. To make her point, the president of The Swedish Association of the Visually Impaired (SRF) uses as an example the needs of deaf-blind members of her own organization, and the needs of members of one organization that includes people with dental injuries. She does not feel the needs of the two groups are comparable. In her understanding, considerably more resources are required to meet the needs of the deaf-blind.

Another common theme is that the scope of the political agenda is different in “access organizations” and “patient organizations”. It is, thus, illustrative that the administrative director of The Swedish National Association for Persons with Intellectual Disability (FUB) explains that the political objective of her own organization is much broader than those of “patient organizations”, such as the Breast Cancer Association. While the latter is considered to have a narrow political agenda, FUB is pointed out as an organization that works with “children and adults [from] zero to 100 years of age, all degrees of intellectual impairments, in every social issue”.

In this way, the distinction between being impaired and not being impaired was problematized by our informants. It was certainly seen as important, but not considered the only division separating “us” from “them”.

Conflicting interpretations about how needs are best met also occur in our material. Different organizations give voice to different interests in discussions about what kinds of political questions should be pursued by The Swedish Disability Federation (HSO). This tends to foster conflicts within the organization. Because of the implications for decision-making, some of our informants considered it problematic that the membership composition of HSO has come to be dominated by “patient organizations”. This was thought to create frictions “in spite of the fact that everybody speaks so nicely about consensus and so on”. The president of The National Association of the Deaf (SDR) explained his view on the question.

The new organizations, they grow like mushrooms out of the ground, and they are patient and diagnosis organizations only. And HSO works on and discusses their issues a lot. They discuss health issues and medical issues. But we fight for different things, you know. We talk about accessibility in society / . . . /. We talk [about] culture, social life, and the labour market. We have a much wider agenda. Today, we are not satisfied with the composition of HSO or the co-operation within it.⁷

We do not mean to imply that the problems described above capture the entire relation between The Swedish Disability Federation (HSO) and its member organizations. Naturally, some of the general political claims made by HSO correspond to claims being made by the studied individual-based organizations. Otherwise they would leave the organization. The point to be made is, instead, that both the heterogeneity among organizations within HSO, and the fact that some member organizations are more similar than others, is bound to create organizational tensions (Ahrne & Brunsson 2005).

One issue now under debate concerns the distribution of resources across member organizations. The issue discussed is the federation’s policy regarding principles for state subsidies. The informants in our study describe, in various ways, this ongoing struggle. The excerpt below, from an interview with the president of The Swedish Association of the Visually Impaired (SRF), may serve as a good illustration. As we have mentioned above, SRF has reflected on joining The Swedish Disability Federation (HSO). However, the president is critical of the present policy on state subsidies. She finds that the adopted policy, i.e. that all organizations should receive the same amount of money

regardless of the surplus costs associated with some impairments, privileges “patient organizations” at the expense of “access organizations”. In her view, the needs of the members of “access organizations” require more organizational resources, since there are not the same kinds of costs associated with arranging meetings and activities in “patient organizations”.

I mean, to take one example, when I get here I have my guide dog. That’s a kind of surplus cost we have. / . . . /When I start my computer I have to have Braille, I have to have speech. / . . . /We have to have escorts, we have to get some help, and all this. I mean you can’t get around that. And I mean there are different degrees of dependence due to type of impairment. / . . . /And we have said this, but twenty-two of the organizations of HSO have said no/ . . . /. And they formed a majority and went to the parliament (*Riksdagen*) and essentially said that they wanted to do away with the surplus costs altogether. And share that money between everyone. And we felt that extremely unfair.

The similarities among “access organizations” have resulted in informal cooperation around political issues of common interest. This kind of collaboration, thus, is based on a narrower collective “we” than the one articulated by The Swedish Disability Federation (HSO). The following quotation from the opening speech held by the president of The Swedish National Association of the Deaf (SDR) at the organization’s conference in 2005 is telling in itself (www.sdrf.se/sdr/verksamhet/kongress).

SDR is a member of HSO. / . . . /But unfortunately, it is difficult to find the right place within an organization with such disparate member organizations. On the one hand, it adds strength to be many [organizations] that adhere to the claims of people with impairments. One example of where we gain from HSO is that it supports us on the issue of sign language. But in our view, there are also many so-called patient organizations and single-issue organizations that take too much room.

The dilemma implicitly touched upon in the above quotation may be phrased in the following way. On the one hand, organizations usually want to increase the number of members. The rationale for this is simple. Firstly, a big organization may be more successful in realizing its social-political programme. This constitutes a main motive for individual-based disability organizations to join The Swedish Disability Federation (HSO). Secondly, more members typically generate more economic resources. On the other hand, more members imply increased heterogeneity. This may in turn render the framing and articulation of political claims more difficult. The reason is, of course, that increased diversity of group identities, needs and interests may also foster internal conflicts. Consequently, heterogeneity renders coordination more difficult and hence threatens to weaken the organization’s capacity to take action. The described tensions between organizations thus reflect difficulties related to size and unity that typically face meta-organizations (Ahrne & Brunsson 2005). This size and unity dilemma is not confined to meta-organizations, however. As will be discussed below it is also faced, to different degrees, by the individual-based organizations.

The Ability/Disability Divide

We have suggested that the collective “we” constructed by The Swedish Disability Federation (HSO) is problematized by “access organizations” in our study. Nevertheless, the ability/disability divide also plays an important role within these organizations. Rules for membership and representation are cases in point. Representation issues concern questions such as which actors are to be granted the legitimate right to interpret members’ needs, who is to have the right to represent the organization in public and who is to be entrusted with the task of handling, administrating and controlling the collective resources of the organization.

The course of events at the annual meeting of The Swedish Federation of People with Mobility Impairments (DHR) in 2001 clearly suggests that such questions are potentially fraught with conflict within the organizations. At this meeting, the entire national board unexpectedly resigned. The immediate cause was that a majority of the delegates at the conference supported a proposal suggesting alteration of the rules for representation in order to enable people without impairments to hold positions on boards and committees. The resigning committee immediately initiated the establishment of a new organization, The Association for Mobility Impaired People⁸ (*Rörelsehindrades förbund*). In this new organization it is established that both eligibility and the right to vote are exclusively reserved for people with mobility impairments.

Rules for representation differ across the individual-based organizations in our study, as do rules for membership. We have discerned two types of membership rules. One type prescribes that members must both experience impairments and support organizational objectives; the other type requires support of organizational objectives only. The Swedish Association for the Visually Impaired (SRF) practises the former kind of rule when exclusively allowing people with a visual impairment to enter the organization. The other organizations practise the latter type of rule and are hence open for anyone who supports the objectives of the organization. We refer to these differences as “narrow” versus “wide” membership groups.

Being admitted to an organization is not necessarily the same as being eligible for decision-making bodies. Two types of rules are discernible in this case also. One is based on the characteristics of the individual member, i.e. that all people holding positions must experience impairments. The other type is based on the composition of boards and committees. This rule requires that a fixed share of the people holding positions must experience impairments.

In two organizations in our study, The Swedish Association of the Visually Impaired (SRF) and The Swedish National Association of the Deaf (SDR), the experience of impairment is a prerequisite for eligibility. In the case of SRF, where all members have visual impairments, everyone is eligible for boards and committees. In SDR, however, there is a wide gap between rules for membership and rules for representation. Whereas anyone who accepts the political objectives of the organization may become a member, only deaf

people are allowed to hold positions on the national board. Consequently, some members are not granted the legitimate right to represent the organization. The Swedish Federation of People with Mobility Impairments (DHR) and The Swedish National Association for Persons with Intellectual Disability (FUB), both of which have wide membership groups, practise the type of rule requiring that a fixed share of the people holding positions must experience impairment. In the case of DHR, it is prescribed that a majority of members on the national board, including the president, must have mobility impairments. Regulations in FUB require that at least one person with intellectual impairments be represented on the national board.

Although rules for membership and representation are different, the studied organizations nevertheless all have some rules suggesting that the presence of people with impairments on boards and committees is considered important. Feminist political scientist Anne Phillips (2003) has coined the expression “the politics of presence” to refer to the kind of thinking implicit in such rules, that is, the belief that the representation of people with certain characteristics is essential. Such a politics has been strongly advocated by both ethnic minority groups and the women’s movement. The argument put forward is that representation of ethnic minorities or women on decision-making boards is important, because the experiences and identities of these social collectivities may be different from those of the ethnic majority group or men, respectively. “The separation between ‘who’ and ‘what’ is to be represented, and the subordination of the first to the second” are thus seen as problematic (Phillips *ibid*:5). In keeping with this, the rules for representation in the studied individual-based organizations imply that “the politics of presence” is an important concept in the disability organizations in this study. The excerpt below from an interview with the president of the Swedish Federation of People with Mobility Impairments (DHR) may provide a good illustration.

A very strong ideology among us is that . . . We are the ones who have the experience of mobility impairments . . . [and the ones who] know what this life is about / . . . / We are the only ones, really, that should represent [the group]. No one without the experience of being impaired should talk about how it is to be impaired.

Centring on the issue of who controls and runs the organization, the distinction between organizations *for* and *of* people with impairments is clearly related to “the politics of presence”. According to Michael Oliver (1990:113) organizations *of* disabled people are “those organizations where at least 50 percent of the management committee or controlling body must, themselves, be disabled”. He also argues that the emergence of the new disability movement in Great Britain in the late 1960s, marks a trend away from support for traditional organizations *for* people with impairments to organizations *of* people with impairments (see also Barnes, Mercer & Shakespeare 1999). This development seems to apply to Sweden as well.

The course of events at the Swedish Federation of People with Mobility Impairments’ (DHR) annual meeting, referred to above, suggest that

questions of representation – who is to have the right to interpret and communicate the needs of the group – are not fixed once and for all. It may not come as a surprise that our data also suggest that they potentially foster conflict. In some organizations with wide membership groups, divisions within the organizations have at times led to more or less open conflicts. The ability/disability divide might then stimulate the construction of two different groups of members within one organization. The course of events in The Swedish National Association for Persons with Intellectual Disability (FUB) is telling in this respect. This organization was founded by the parents of children with intellectual impairments, and parents have ever since been very influential within the organization. However, in 1995, members with intellectual impairments decided to establish the section *Klippan* to increase their own influence within FUB. The idea was born out of dissatisfaction with things as they were, according to one of the initiators of the establishment of the new section. He recounts to us that the process began in the 1980s when “it was decided that persons with intellectual impairments should take positions in committees, and stuff like that”. Experiences gathered at meetings were not always positive, because “we often became hostages because the committee meetings were held on a far too high level for my buddies to keep up with”. The result was that people with intellectual impairments felt that they did not have the opportunity to communicate sufficiently their own experiences and perspectives within the organization.

That's when we began to think about how to increase the influence of persons with intellectual impairments. We appointed a group consisting of, I think, three or four persons. /.../This was in 1995... so we proposed to establish something we called *Klippan*.

One of the main motives behind establishing the new section was to empower people with intellectual impairments and to enable members of this group to interpret and articulate their own needs and interests. The section aims at allowing people with intellectual impairments “to be adults and to emancipate themselves from their parents” in order to deal with problems “on their own terms” (www.fub.se/Klippan).

Members with intellectual impairments apparently draw a line between themselves and the non-disabled members of the organization. With the establishment of *Klippan*, this division was institutionalized in the formal organizational structure. Moreover, the process made manifest differences in opinion about social-political issues. To take just one example, we were told that the two different groups display different views on the question of foetal diagnosis. Our informant said that the board of the national organization, which consists mainly of people without impairments, had not taken a clear enough stand on this issue. In his opinion, FUB ought to fight against foetal diagnosis “because me and many of my friends think about it as a way to do away with people you don't want”. He believes that group differences in opinion are due to divergent experiences.

[The national board] is composed mainly of parents . . . And they of course get their viewpoints from their own experiences, whereas my friends and I form our opinions . . . from our experiences, so to speak. So, you proceed from very different experiences.

The history of the establishment of *Klippan* brings to the fore a problem, i.e. that procedures for decision-making may function as barriers to equal participation (Fraser 2003). In this case, a group of members successfully argued and acted in order to be empowered and recognized in their own right. They chose to protest to express dissatisfaction and to bring about organizational change. The group of people that resigned from the national board in order to establish a new organization, which was referred to in the beginning of this section, preferred another strategy. Instead of choosing the voice option to protest against the state of things, they chose the exit option (Hirschman 1970).

Intersecting Social Divisions and Parity of Participation

The examples given in the previous sections help to illustrate some of the complexities confronting disability organizations in their struggle for social justice. That is, that the heterogeneity of the movement and diversification of group identities sometimes give rise to hidden or open conflicts concerning representation issues. They also make clear that claims for recognition and redistribution are raised not only in relation to the welfare state, but that there is also an ongoing struggle over resources and needs interpretations between disability organizations and between various social groups within the movement. Thus far our analysis has mainly been confined to examining ways in which type and degree of impairment may affect group identities, needs interpretations and political claim making. We agree, however, with feminist disability researchers pointing out the need to deal with the intersection of disability with gender (e.g. Barron 1997, 2004, Morris 1996, Thomas 2002, Traustdóttir 2004, Verner & Swain 2002). Starting out from the assumption that “disabled women occupy different kinds of social locations to disabled men, because more than one system of oppression is in operation” (Thomas 2002:48), the following section, consequently examines intersections between disability and gender.

We may begin by establishing that the existence of informal power structures is discernible simply by looking at the organizational charts of the individual-based organizations in our study. Within the respective organizations, there are sections, networks, projects, etc. dealing specifically with particular experiences and problems facing women, young people and people born outside Sweden. That is, these groupings are founded on major social divisions in society, such as gender, age and ethnicity. The very existence of these kinds of arenas suggests the complexities and power relations involved in the interpretation and articulation of members’ needs.

Sociologist R. W. Connell (1987) has developed the concepts of “gender order” and “gender regime” in order to distinguish between the structural inventory of an entire society respective the structural inventory of particular

institutions (ibid:98–99). The division of labour, the structure of power and the structure of cathexis (sexual social relations) are seen as major elements at both levels. We find Connell's attempt to develop a concept for the intermediate level of social organization fruitful, and will here use the term "gender regime" to denote the given state of play in gender relations at various institutions. Two types of gender regimes will be discussed. On the one hand, gender regimes in the Swedish welfare state. On the other hand, gender regimes in the investigated disability organizations. Whereas the former tend to produce gendered outcomes in services, entitlements, employment, etc., the latter tend to produce and reproduce gendered organizational structures, practices, and social justice claims.

Several studies have demonstrated a gendered distribution of resources among people with impairments. Compared with men, women have generally less access to money, more health problems, face more difficulties in getting access to rehabilitation and advanced technical aid, and are more likely to be unemployed (e.g. SOU 1999:21:118). Our informants generally seemed to be well aware of the gendered distribution of resources, although some appeared somewhat disinclined to discussing gender issues. Others seemed to attach great importance to these kinds of questions. For instance, they pointed to gendered interactions between public service workers and people with impairments as one possible explanation of the fact that women, to a lesser degree than men, get access to resources. That is, gendered expectations from public service workers combined with differences in women's and men's ways of expressing themselves were considered an important mechanism underlying these gendered outcomes. We were informed about a presumed tendency among the (often) female public service workers to "feel sorry for the men", whereas they expect women to "manage the things they themselves have to manage", such as a job, domestic work, small children, etc. According to one informant, they are inclined to "forget that the woman applying for assistance/.../has an impairment".

The vice president of The Swedish Disability Federation (HSO) underlined the necessity of attending to gendered outcomes "when it comes to transportation service, when it comes to means of assistance, when it comes to social insurances, when it comes to work". She regretfully admitted, however, that a gender perspective is often missing within her own organization, both in discussions about members' needs and in discussions about which policy to pursue.

Gender regimes within disability organizations was a topic much discussed by the president of Forum – Women and Disability (*Forum – Kvinnor och handikapp*). She recounted to us that women tend to be both silenced and ignored within the disability movement, and that "women's questions" are not put high on the political agenda. The absence of a gender perspective together with the gendered maldistribution of resources actually formed the main motives for establishing this meta-organization in 1997 (which among other organizations includes SDR, DHR and SRF). The aims of Forum are both to increase women's influence over their respective disability organizations, and to improve the overall life situation of girls and women with

impairments, including questions of bodily integrity, such as violence (www.kvinnor-handikapp.se).

Some informants addressed recognition issues in terms of organizational practices that imply disrespect of women. For example, one informant communicated to us that it is “easier to be a man than it is to be a woman”.

They listen more to a man. I don't know why. A woman must somehow always prove that she knows what she's talking about. A man doesn't have to do that. If he says that “I can do that, and that, and that”, they don't question it. But a woman must somehow prove that she can do the thing she just said. It is very odd.

Another informant drew parallels to the gender order in society as a whole, when bringing up the question of organizational gender regimes. Her intention was apparently to disclose that visually impaired men and women are not participating on equal terms within the organization.

Why should it be the case that people with visual impairments are treated alike, when other men and women are not? There is somehow a difference. We know that. People often say that Sweden has come a long way when it comes to gender equality. And we have, compared to many other countries. But still, I think we have a long way to go. And this includes SRF, I think. / . . . / Somehow men still have . . . the power.

As implied above, however, there are, or have been, projects and/or networks within the investigated organizations, sections that concentrate specifically on gender issues. However, when considering the priority given to and resources invested in gender issues, it becomes apparent that there is substantial variation across the organizations in our study. In some of them these kinds of activities are temporary in nature, whereas they are considered to be of primary concern to others. To our knowledge, The Swedish Association of the Visually Impaired (SFR) presently puts gender issues higher on its political agenda than do the other individual-based organizations. We will henceforth mainly use examples from this organization when discussing ways in which gender may intersect with disability in social justice claims articulated by the disability movement.

Gender struggles have a long history within The Swedish Association of the Visually Impaired (SFR). The present president recounted, however, that whereas gender was a vital issue roughly 50 years ago, it was eventually considered obsolete due to the growing influence of a gender-neutral discourse.

We had a strong focus on gender equality work during the 1950s and 1960s, I think. At least during the 1950s. But then it was closed down and it was said that, “well, we don't need to work toward gender equality since we work toward everybody's equality in society”. “We don't make distinctions . . . it's important to work for everybody, we should not differentiate between people”. So it [gender equality work] was closed down.

The work toward gender equality was, however, taken up again in the 1990s. Influential people within the organization felt that it had “lagged behind the other women's movements in Sweden” and hence was “not in

phase”, considering that “male dominance was strong, both in chairmanships around the country, and on the national level”.

I am the first female president. So it took 115 years until that became possible. There have been active women on the board, but they have been secretaries or have had other traditionally female assignments.

Female members of The Swedish Association of the Visually Impaired (SFR) have insisted on political, ideological, economic and social change both inside and outside the organizational context. Moreover, people holding leading positions have called attention to male hegemony within the organization. For example, some years ago, the former president explained, in an editorial in the membership journal, that The Swedish Association of the Visually Impaired (SFR) had not taken seriously the discrimination facing women within the organization. He acknowledged that it had not been fully understood that the kinds of discriminating mechanisms active in society at large, are also active in SRF (*SRF-Perspektiv*, 2001). In keeping with this, the present political program explicitly states both that differences in living conditions between visually impaired men and women must be illuminated (in order to be eliminated), and that gender equality politics imply that organizational resources must be redistributed from men to women. Moreover, it emphasizes the need to acknowledge women as a social group in their own right, that is, to recognize and revalue the “difference” and presumed values, experiences and competences of women.

In its plan for gender equality, The Swedish Association of the Visually Impaired (SFR) is described as a male-dominated organization, and the need to increase the representation of women on boards, committees, work groups, etc., is strongly underlined. Consequently, “the politics of presence” in disability organizations not only concerns the question of the extent to which people without impairments can represent the interests of people with impairments (see above), but also the extent to which men can rightly interpret and represent the needs respective interests of women. The presence of women in the decision-making process has indeed become a political issue within SRF.

Since men held all leading positions, they could make decisions among themselves in pretty much closed rooms, and then present ready-made propositions . . . And it then becomes difficult to pursue another policy. / . . . /We felt that [even though] two-thirds of the members of SRF were women they didn't get two-thirds of the resources. And that [gender] questions were typically not focused on. And then we felt that “something is wrong here”.

One rationale behind the idea of a politics of presence is that marginalized social groups need to hold positions in decision-making boards so that their needs and interests will be articulated and eventually met. However, the existence of depreciative value patterns may render mere presence insufficient. The history behind the establishment of *Klippan* within The Swedish National Association for Persons with Intellectual Disability (FUB) is one example of this (see above). This problem was also brought up during discussions about gender issues. One informant reminded us that influence is

not only a question of being present, but also of “daring to say something” and “someone listening” to what you have to say. The president’s answer to the question how it came about that The Swedish Association of the Visually Impaired (SFR) resumed work toward gender equality in the 1990s is quite elucidating in this respect.

It was also because . . . to the extent that they had a position on the board, women felt that it was not on equal terms. They didn’t listen as much to women, and [they] used techniques for dominance. It was completely okay to ridicule a woman, or to not pay attention to what a woman said. To sort of conceal the weight of [what was said] . . . or to strengthen what men said. There were a lot of these kinds of techniques played out.

The quotation above tells us about stories about men who, consciously or unconsciously, withhold information from women, belittle them and make them “invisible”. Techniques such as these are well known to gender researchers as powerful mechanisms for ensuring male dominance.

To avoid the kinds of situations described above, subordinated groups sometimes form discursive arenas in which they can “invent and construct counter discourses” that permit them to formulate “oppositional interpretations of their identities, interests, and needs” (Fraser 1997:81). The formation of counter publics is also used as a way for the less powerful to avoid the risk of being absorbed into a false “we” that reflects the more powerful (*ibid.*). Naturally, the purpose behind the establishment of *Klippan* may also be understood in these terms. That is, it aims at providing an opportunity for people with intellectual impairments to interpret their own needs and interests. The strategy to form counter publics has been practised a great deal by the wider women’s movement, and is apparently also used by female members in disability organizations. One of our informants informed us about the undertaking to form a new counter public within one of the studied organizations.

I don’t really know what we will do. Arranging seminars, [where] women can meet to discuss their issues. Because often they don’t dare to voice certain questions when men are listening. They [the men] take over. Things like that. I think it would be good to meet alone sometimes. Not to exclude men, but I mean to meet women only. To talk about things we like to talk about.

Establishment of The Forum – Women and Disability in Sweden is one example of a counter public within the disability movement. Another example is the formation of national networks such as *Lina*, which was initiated by women in The Swedish Association of the Visually Impaired (SFR) to “encourage women” and to integrate them into the “masculine structures that characterize the organization”. This network is, in turn, a member of the European Association *Daphne*, which was formed to defend the interests of women with visual impairments, and in particular, the interests of women who are the victims of violence. One of the objectives of the network is to collect information on cases of violence faced by visually impaired women, and to raise awareness of the violence faced by women among the public and strategic stakeholders.

Concluding Remarks

In this article Nancy Fraser's conceptual framework has been used to analyze social justice claims articulated by Swedish disability organizations struggling to improve the living conditions for people with impairments. It has pointed to complexities confronting the disability movement in its struggle for social justice. The study has shown, first, that in their struggle for parity of participation these organizations insist that welfare provisions should reflect impaired people's own interpretations of their needs. It also suggests that disability organizations balance claims for cultural recognition and economic redistribution differently. While some put approximately equal weight on the two types of justice claims, others tend to accentuate the need for redistribution *or* the need for recognition.

Secondly, our analysis has indicated that the concepts of "redistribution" and "recognition" are productive, not only in understanding differences in disability organizations' claim-making towards the welfare state, but also in understanding struggles between and within these organizations. It has suggested that struggles over needs interpretations, over representation and over economic resources go on within the disability movement: between "old" and "new" disability organizations, between members with different genders and between members with and without impairments. Our study has, thus, indicated that the need for recognition and redistribution is not a question exclusively concerning the relation between people with and without impairments. Instead, it has pointed out that questions concerning the construction of group identities (who are "we"?), claims for social justice (what do we want?), and representation (who can legitimately speak for us?) are indeed much more complex.

A third suggestion in this article has been that intersecting power structures, such as gender regimes, are at work in the disability movement. Focusing specifically on gender it has been proposed that the gendering mechanisms in society at large are also productive in organizations that make up the movement. The results from this study accordingly give support to Fraser's assertion that "parity of participation" may be a fruitful concept for assessing both the relative standing of minority groups compared with majorities, and practices at the intragroup level. In other words, one interpretation of the results from our study is that parity of participation within the disability movement requires changes in practices and power relations between genders.

A fourth suggestion has been that power differences in access to resources, respect and influence sometimes give rise to conflicts and struggles between different groups of members. Women's claims to increase their representation on decision-making boards, i.e. for "a politics of presence", has provided one example of ways in which disadvantaged groups within the disability movement at times take action to remove barriers to equal participation. Attempts to increase impaired people's representation and power in disability organizations have provided another example. The formation of counter publics where groups of members exchange their own experiences and formulate group specific interests is a third example of actions that challenge existing power structures in the disability movement.

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Notes

- ¹ Some researchers stress that the disability movement shares with other “new social movements” the features of being located at the periphery of the traditional political system; of offering a critical evaluation of society; of stressing “post-materialist” values; and of being concerned with issues that cross national borders (e.g. Oliver 1990:118–123).
- ² We use the respective organization’s official translation into English here.
- ³ With the exception of The Swedish Association of the Visually Impaired (SRF), the individual-based associations in our sample are all members of HSO. However, SRF was also a member of HSO some years ago, and the question of joining it again is presently the subject of considerable debate.
- ⁴ Our point of departure is taken in Fraser’s theory, which emphasizes that discourses over needs function as a medium for the making and contesting of political claims and “appears as a site of struggle where groups with unequal discursive and non-discursive resources compete to establish as hegemonic their respective interpretations of legitimate social needs” (Fraser 1989:166). Hence, our emphasis on needs interpretation in no way contradicts the critique against a needs-based welfare provision, i.e. that this kind of provision may not only open way for professional domination of welfare provision, but also institutionalize discrimination.
- ⁵ Maybe somewhat paradoxically, this does not seem to prevent SDR from identifying with the disability movement. In this respect the relationship between the two seems to differ substantially from the one between Deaf people and the British disability movement. According to British disability researchers the former group does not at all identify with disability movement (Barnes et. al. 1999:204).
- ⁶ Other terms that were used are “traditional”, “classic” and “old organizations” versus “diagnose”, “medicine” and “new organizations”.
- ⁷ When regarding the disability movement as a “new” social movement, we face a kind of paradox here. That is, in our study the old organizations, rather than the new ones, seem to be part of a “new” disability movement (Oliver 1990).
- ⁸ This is our translation.

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