

Nothing About Us Without ... Who? Disability Rights Organisations, Representation and Collaborative Governance

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ABSTRACT

When governments invite disability rights organisations to policy deliberations, how does the slogan ‘nothing about us without us’ translate into practice? This article draws upon a study about local disability organisations and their relationship to a regional consultative citizens’ council on disability issues in Sweden. Interviews were conducted with organisations that had seats on the council, politicians and officials on the council, as well as with disability organisations without seats on the council. Results show that conceptualisations of ‘disability’ in policies that regulate deliberations not only define what type of organisations are eligible for appointment to the council, but also influence how disability organisations identify, present themselves and what issues they advocate for – leading to divisions among organisations. The findings have implications for collaborative governance structures and disability rights organisations elsewhere – problematising issues around representation, institutionalisation of inclusion and the constantly evolving concept of what counts as ‘disability’.

KEYWORDS

Disability rights; advocacy organisations; disability movement; public participation; social policy; political representation

1. Introduction

In recent decades collaborative governance – structures where citizens participate in deliberative decision-making processes – have become almost naturalised in public policy-making in Western representative democracies (Fung, 2015). They range from public hearings, consultations and advisory boards to partnerships and collaborative decision-making (Ansell & Gash, 2008; Beresford, 2010; Frawley & Bigby, 2011; Omeni, Barnes, MacDonald, Crawford & Rose, 2014). This is often termed as

‘deliberative democracy’ – an expansion of representative democracy (Carpini, Cook & Jacobs, 2004).

In Sweden, the relationship between authorities and civil society organisations rests largely on the so-called Scandinavian ‘corporatist’ tradition, which is a good example of how state policy mandates and influences different citizen groups’ opportunities to participate in the democratic processes (Christiansen et al., 2009). This tradition can be understood within a democratic/social rights discourse of citizenship, where participation is both a goal in itself and a means to achieving this goal (Askheim, Christensen, Fluge & Guldvik, 2016). Both parties share an interest in this governance structure. Being invited to the decision-making process offers organisations the possibility of directly influencing policy-makers, and gives policy-makers first-hand access to specific knowledge while simultaneously legitimising their decisions.

This article analyses disability rights organisations’ involvement in collaborative governance, which is of particular importance since disabled people are underrepresented as members of political parties and have a significantly lower voting turnout, largely due to inaccessibility (Teglbjærg, Mamali, Chapman & Dammeyer, 2021).^{*1} Nevertheless, organisations that represent disabled people have a long history in many countries of being active participants in policy processes at all political levels (Caldwell, Hauss & Stark, 2009; Chaney & Fevre, 2001; Lewin, Lewin, Bäck & Westin, 2008; McColl & Boyce, 2003; Priestley et al., 2016; Thill, 2014). Especially in the last decade, disabled people’s representation has become a prioritised policy area, notably in the UN Convention on the Rights of Persons with Disabilities (CRPD). Article 4:3 establishes that ‘States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations’ in decision-making processes concerning ‘issues relating to persons with disabilities’.

The Scandinavian system encompasses a formal financial support structure consisting of special funding allocated to national civil society advocacy organisations (statsbidrag). At the regional and municipal government levels there are similar structures. Consultative citizens’ councils relating to disability issues are the most common type of council in municipalities (Folkbildningsrådet, 2011; Socialstyrelsen, 2012), following recommendations in a government report from the 1970s aiming to reform disability policy (SOU, 1970:64). The council system became increasingly common after the so-called Democracy Inquiry (SOU, 2000:1), which suggested that democratic participation in between elections needed strengthening.

As empirical work has shown, however: ‘the intention to be inclusive is not necessarily matched by the practices that inform the establishment of such forums nor the processes of dialogue within them’ (Barnes, Newman, Knops & Sullivan, 2003: 381). Instead, discursive and participatory practices can potentially exclude particular groups or individuals from deliberations (Sher-Hadar, Lahat & Galnoor, 2020). There are a wide range of factors relating to inclusiveness in collaborative governance, including issues to do with trust, relationship building and leadership (Ansell, Doberstein, Henderson, Siddiki & ‘t Hart, 2020).

At an organisational level, challenges may include lack of resources, for example in terms of personnel, time, economy or skills (Ansell & Gash, 2008). This is relevant to consider with regard to disability rights organisations that work not only with these kinds of representational tasks, but also with individual support and services. One key challenge is therefore that members may not be interested in participating in advocacy activities, as their reasons for joining an organisation may be related to empowerment, information about a certain impairment or condition – or simply community (Barnes, Newman & Sullivan, 2006; Caldwell, 2011; Charlton, 1997). Another aspect concerns the increasing engagement in disability advocacy online, which has led to difficulties in recruiting new members to the traditional organisations and regrowing the membership with younger generations that more often engage online (Gelfgren, Ineland & Cocq, 2021; Qu & Watson, 2019; Trevisan & Cogburn, 2020).

Individual challenges include inaccessibility, difficulties related to impairment effects, or financial strains for members participating as volunteers (Beresford, 2013; Johansson, 2019; Simmeborn Fleischer, 2015).^{*2} Finally, there may be ideological or generational differences among members in an organisation which can impact upon whether and how certain advocacy work is conducted (Griffiths, 2019; Hugemark & Roman, 2007).

This article reports on a case study of the Council on Disability Issues in the regional government of Västtra Götaland, Sweden, carried out in 2016. The case study was chosen by the Council on Disability Issues and its members, that is, representatives of disability rights organisation in the region. These organisations wanted to learn about how their practices in the policy deliberations could be understood in a wider sense, and how their work could potentially improve. The regional government financed the research and I was commissioned to conduct it according to my proposed study design, without any other influence over the research process. The project resulted in a comprehensive report (Bahner, 2017) and a conference for relevant stakeholders in the region.

In this article, I focus on two specific issues. First, I analyse how disability definitions in the policies for collaborative governance influence disability organisations' advocacy work and possibilities for participation. Second, I explore how disability is conceptualised among a range of disability rights organisations, and what consequences different organisations' conceptualisations have for their collaborations with each other and with the Council. The article discusses possible consequences of institutionalising disability organisations' influence in collaborative governance, and how such practices that aim for democratic participation and influence can be understood 'under conditions of structural inequality' (Young, 2002: 4). In other words: how are disability issues framed in a policy context which aims to further disabled people's inclusion – in a society that is inherently disabling and ableist (Campbell, 2009; Oliver, 1990)?

I will argue that the ways in which the Council on Disability Issues has administratively defined disability have led to unequal representation among different types

of disability organisations. But this is not only relevant to this specific Council; the case study illuminates broader issues around disability definitions, disabled people's representation in deliberations, and how collaboration among disability rights organisations is influenced by policy structures. The results can therefore be useful to disability rights organisations elsewhere, both in their advocacy work and when choosing strategies for collaborations – as well as for understanding wider issues around disabled people's democratic participation.

The article is structured as follows: first, the case study will be contextualised within Swedish collaborative governance practices as well as the evolving nature of the disability movement. Second, I introduce the theoretical framework and following that the methods, analytical tools and ethics will be discussed. Then the findings will be discussed in four thematic sections and, finally, I discuss the results and some ideas looking forward.

2. A Changing Disability Movement in Sweden

The Swedish disability movement was formed in the 1960s and 1970s during times when disabled activists criticised 'traditional' disability organisations which were controlled by non-disabled people and were often reliant on charity (Sépulchre & Lindberg, 2019). More and more organisations adopted a politicised view of disability, which has been theorised as the Nordic 'relational model of disability' (Tøssebro, 2004). However, compared to the UK social model, which emphasises oppression, Swedish disability activism is less confrontational and conceptualises disability as societal 'shortcomings' – a perspective that has had significant impact on policy (Berg, 2005). One reason can be owed to the corporatist tradition where disability organisations have benefited from being an established dialogue partner with the state. In other words, it is clear how the development of disability movements is highly contextual (Callus, 2013; Nuth, 2018).

These developments can be seen against the background of other changes in the field of disability-related organisations in Sweden. For instance, self-advocates with intellectual disability have challenged traditional parent-led organisations (Mallander, Mineur, Henderson & Tideman, 2018) and cross-disability organisations based on sexual identity or gender have emerged as a reaction to unequal representation (Hugemark & Roman, 2007). So-called 'patient organisations' encompassing both general health care and mental health services users (including the survivor movement) are also increasingly demanding influence among 'traditional' disability organisations (Markström & Karlsson, 2013; Söderholm Werkö, 2008).

This separation of identity and organisation is not unique (Beresford & Branfield, 2011) but can in Sweden be understood against the background of a national policy reform of the care and services for 'people with psychiatric illnesses or disabilities' (SOU, 2006: 100). It led to new laws and regulations concerning service user involvement in the health care and mental health services requiring individual rather than organisational representation (Mossberg, 2016). In other words, there are inherent conflicts of interest based on differences among groups based on impairment type,

disability ideology as well as intersectional positionings – core challenges for the disability movement (Beckett, 2006a; Charlton, 1997). Specifically with regard to advocacy, the way that policy issues are framed reflects underlying group identities of a ‘disabled person’ which may not always be representative of a wider disability experience – or allies more broadly (Kelly, 2010). Representational issues are further complicated by the fact that many disabled or chronically ill people do not identify with a political disabled identity (Watson, 2002). These issues must therefore be taken into consideration when analysing processes of inclusion of disability rights organisations in policy deliberations.

3. Social Justice and Disability Representation: A Theoretical Framework

Fraser’s (2008) theorisation on justice is useful for analysing challenges to equal participation in democratic processes, including for disabled people, as exemplified in the work of Mladenov (2017). Even though Fraser (2008) aims to analyse certain issues around (in)justice in a globalised world, her concepts are also relevant to analysing governance structures on local or regional levels (*ibid.*). I have chosen to use her framework for analysing the current data for this reason. Fraser’s theory of justice is three-dimensional, comprising three equally important and intersecting dimensions: economic redistribution, cultural recognition and political representation – questions which are highly relevant to both historical and current disability scholarship and activism (e.g. Oliver, 1990). Fraser argues that ‘the ability to exercise one’s political voice depends on the relations of class and status’ (2008: 165). In this article I focus on aspects concerning political representation, but this cannot be understood fully without considering the influence from the other two dimensions.

Fraser discusses political representation as a central component of ‘parity of participation’, in relation to its opposite; political injustice as ‘misrepresentation’. She offers two different levels of misrepresentation, where the first one concerns the failure of political decision rules to include everyone fully, i.e., ordinary-political misrepresentation. This can be translated to disabled people’s structural disadvantage in most democratic societies in terms of not being fully represented in the public and political spheres. The second level she calls ‘misframing’: ‘when questions of justice are framed in a way that wrongly excludes some from consideration’ (*ibid.*: 19). Consequently, certain groups may lack the voice to advocate for and claim justice, such as economic redistribution or cultural recognition. In other words, ‘the political dimension is implicit in, indeed required by, the grammar of the concept of justice’ (*ibid.*: 21).

Misframing can be analysed from three aspects: the ‘what’, the ‘who’ and the ‘how’ of justice. What can justice claims concern? Who counts as a subject to make claims? And finally, how can justice claims be processed? These are the ‘meta-political’ aspects of injustice, which are often decided upon by people in powerful positions rather than by individuals and groups who are concerned by the very justice claims. As such, Fraser’s (2009) concept of political representation goes beyond

traditional work on democracy focusing on obstacles to participatory parity, since ‘the relations of representation were *per se* unjust’ (146, italics in original). Based on her ‘all-subjected principle’ she further argues that ‘all those who are subject to a given governance structure have moral standing as subjects of justice in relation to it’ (ibid.: 65). Against this background it is important to analyse administrative and policy-related boundaries around disability definitions in collaborative governance, as is the focus of this article. But first I present the research design of the study upon which this article is based.

4. Research Design

The data presented here is part of a larger research project that mapped and characterised disability rights organisations in region Västra Götaland and analysed how the organisations experienced their possibilities to influence the region’s policies and services, specifically in relation to the Council on Disability Issues (Bahner, 2017). The article draws on results from (1) policy analysis of the regional administration’s collaborative governance regulations; (2) individual interviews with two officials working in the Section on Human Rights and responsible for the Council; (3) a focus group discussion with 10 of the 11 organisations that were appointed to the Council;*3 (4) a focus group with the three appointed councillors, and finally; (5) interviews with 22 disability organisations that were *not* represented on the Council. This mixed-methods approach is common in social movement studies whereby different types of data complement each other and offer a broader perspective on the studied phenomenon (Della Porta, 2014).

The focus group with the 10 organisations in the Council concerned conceptualisations of disability, views of the disability movement, principles of representation, and possibilities to influence the regional administration from ‘the inside’. Furthermore, individual follow-up questions were sent to the representatives via email afterwards. With the three politicians, the focus group discussion concerned their views on disability concepts and organisations, and their role in collaborative governance. The individual interviews with the two officials aimed both to elicit information about the deliberative governance structures, as well as to encourage them to reflect on how the structures influenced different types of advocacy.

Most of the 22 organisations without representation in the Council were traditional non-profit membership organisations, but apart from these, there was also an independent living organisation, two integrated theatre and dance companies, a work integration social enterprise, two sports associations and an umbrella organisation. This was a purposive sample to create diversity, both in terms of impairment and organisation types. The interviews covered a wide range of issues relating to the larger study that this article is based on, namely advocacy issues, activities, methods and strategies. The focus in this article concerns specifically the organisations’ views on their positions in the disability movement, how they conceptualise disability, and their experience of opportunities to influence the regional administration from their ‘outsider’ position.

I conducted semi-structured interviews by posing open-ended questions encouraging interviewees to talk freely about the topic (Kvale & Brinkmann, 2014). In this article I use social constructionist analysis (Burr, 1995) to address questions of how disability as a social phenomenon is (re)produced in regional policy and used in social interactions, claims-making and identity work by disability organisations. My focus lies on what is said about disability in governmental policies and by representatives of disability rights organisations. I am less interested in personal narratives but rather in how disability is talked about for strategic purposes in relation to the Council for Disability Issues. My analysis is inspired by the ‘What’s the Problem Represented to be?’ (WPR) approach:

By asking how ‘problems’ are represented or constituted in policies, it becomes possible to probe underlying assumptions that render these representations intelligible and the implications that follow for how lives are imagined and lived. (Bacchi & Goodwin, 2016: 6)

This approach enables investigation of power relations related to disability oppression from material, cultural and political perspectives (Campbell, 2009; Kafer, 2013; Oliver, 1990), that is, how discursive conceptualisations of disability produce certain policies and organisational priorities – but more importantly, how they affect disability organisations’ participatory opportunities.

The project was commissioned and financed by the Västra Götaland region’s Human Rights Committee as part of their ongoing development work for policy and practice. They developed the project idea together with the Council on Disability Issues, with several aims: to deepen their knowledge about the disability movement in the region, including its relationship to the Council and possibilities for influence, and to share this knowledge more broadly to inspire both policy makers and disability organisations. When the Committee and the Council had chosen my proposal, I was hired to conduct the study from 2016 to 2017 by Research and Development West with the Gothenburg Region Municipal Federation (FoU i Väst/GR), which similarly conducts development work for policy and practice. As such the research was not subject to the ethical procedures required for university-based research at the time of study, but I followed ethical principles adopted by the Swedish Research Council (Vetenskapsrådet, 2011). Specifically, participants were anonymised and only mentioned as Official, Councillor or Representative of Organisation X. They received information about the project and its aims, as well as their rights as research participants to opt out at any time without reason. Verbal consent was obtained from all voluntary participants and was audio-recorded, and they were offered a transcript of their interview.

The difficulty with offering complete anonymity was discussed with all participants, since representatives most likely knew of each other, and a curious reader could easily find out who is the main representative of an organisation from their website. However, it was deemed that the nature of the themes discussed were not of a controversial nature; in fact it was in their organisations’ best interest to contribute to developing their possibilities for influence. Furthermore, they spoke as representatives of an

organisation, that is, a certain membership base as well as democratically agreed upon opinions. Finally, based on the Council's aim to use the research findings in broader development work, they consented to making the Council and its work known across Sweden and internationally, including through a report in Swedish (Bahner, 2017), jointly organised conference and the present article.

With regards to my own positionality and its impact on the research, I was already known to some of the organisations as a non-disabled researcher-activist ally from my previous university-based doctoral work. In my position at a municipal research and development unit where I was hired specifically for this project, my purpose was to conduct the project according to the aims of the Council by contributing with my research expertise. Through a continuous dialogue with a representative of the Committee on behalf of the Council, I sought to mitigate any potentially negative impact of my non-disabled positionality.

5. Findings

The first two sections present a contextual and historical analysis of the Västra Götaland region's unique work with deliberations, including a policy analysis of regulations at the time of study. Subsequently, the analysis of interviews and focus group discussions resulted in four themes that offer different views on how disability can be understood and what consequences it may have for collaborative governance: (1) administrative and political views; (2) collaboration between disability organisations; (3) competing disability definitions among organisations; and (4) representation.

5.1 Region Västra Götaland and the Council on Disability Issues

Västra Götaland became the first regional government to implement a political committee related to disability issues in 1999, 'the Handicap Committee'. The main objectives were to mainstream disability perspectives within its administration and services, and to empower disabled individuals through special service delivery and participatory initiatives (Handikappkommittén, 2010). The committee worked on behalf of the regional administration's governmental board and its members were appointed politicians (councillors) with their own administration. They met with the Council on Disability Issues comprising representatives from 16 disability rights organisations.

In 2011 'the Handicap Committee' turned into the Committee on Human Rights, aiming for similar processes of mutual knowledge exchange in policy-planning and decision-making. Administratively it sits under the regional government's Human Rights Section. The Committee on Human Rights hosts several theme-based Councils, one of which is the Council on Disability Issues. At the time of the study, representatives from 11 organisations had seats on the Council. It is noteworthy though that the 11 members are no longer elected as representatives of their organisations, but as representatives of five groups of 'difficulties' (svårigheter): persons with difficulty seeing; hearing; moving; tolerating certain substances; and processing, interpreting and conveying information.*4 The representatives receive

a remuneration when attending meetings and they are also compensated for any travel costs, but not for any loss of income.

The state funding to national ‘disability or patient organisations’ provided by The National Board of Health and Welfare, requires that they operate as traditional membership organisations based on certain democratic structures such as elected boards, and that they have regional and local branches. The regional regulations for collaborative governance procedures and financial support are clearly affected by the state’s policy, defining eligible organisations as democratically structured non-profit membership organisations with at least 100 members in at least 8 municipalities of the region. At the time of study 91 organisations received funding from the region, comprising both so-called organisational funding, for which they are eligible based on organisation status, and activity funding, which requires that organisations execute certain agreed-upon activities. It is also possible to apply for short-term project funding and funding to start a new organisation. Additionally, three umbrella organisations received so-called collaboration funding.

The main umbrella for disability rights organisations in the region is the national Swedish Disability Rights Federation’s regional branch Funktionsrätt (Disability Rights) Västra Götaland.*5 They have 57 local member organisations and receive regional funding. The membership is mostly made up of traditional organisations, but new organisation types have been emerging in the recent decade. For instance, the activity-based organisation Passalen is a provider of accessible activities to ‘children and youth with functional variations’, in part commissioned by a municipality. They do not mention advocacy, but their activities are described as based on the CRPD and the UN Convention on the Rights of the Child. Thus, their services can be seen as advocacy in practice, or social activism (Haslett & Smith, 2019). As will be discussed below, such developments present challenges to collaborative advocacy work, representation and influence. Not least with regards to an up-and-coming alternative umbrella organisation in the region representing mental health organisations, organised within a national umbrella, the National Partnership for Mental Health (NSPH), which will be discussed further below.

5.2 Evolving Disability-Related Terminology

In order to understand some of the discussions among members of the Council for Disability Issues which will be presented below, I here give a short overview of some recent developments with regards to disability-related terminology, based on the policy analysis of regulatory documents relating to the Council. The Västra Götaland regional administration recently updated the financial support system for disability organisations. The previous ‘support to regional handicap and patient organisations’ was changed to ‘disability organisations and patient organisations’ and ‘organisations representing people with impairments/functional variations or patients’. Like elsewhere, the word ‘handicap’ (handikapp) is increasingly being replaced with ‘disability’ (funktionshinder). This is in line with recommendations by the Swedish National Board of Health and Welfare

mentioned earlier, a government agency under the Ministry of Health and Social Affairs that is, among other things, responsible for disability support policy and terminology (Socialstyrelsen, 2021).

The Board recommends using two words that have similar meanings as impairment and disability: 'funktionsnedsättning', meaning 'function-lowering', i.e., a medical and individual perspective, equivalent to impairment, and 'funktionshinder', meaning 'function-hindrance', i.e., a social and relational understanding, equivalent to disability. A person with 'function-lowering' is described to be 'function-hindered' only if there is inaccessibility in the surroundings. Grue (2015: 11) describes this as 'the gap model'. It is also known as the Scandinavian 'relational model' (Tøssebro, 2004). Swedish disability policy aims to minimise the gap between impairment and disability by providing special services (Lindqvist, 2017).

As Grue (2015) points out, disability concepts are highly contextual, and their meaning must therefore be thoroughly examined in their specific cultural context. In Sweden (and the Nordic countries), this must be related to the general welfare state, where the administrative definition of disability has been very influential in the disability movement and its strategies for advocacy, as well as how the state has institutionalised civil society influence (Söder, 2013). This is in contrast to (for example) the American minority model and the British social model, where confrontational advocacy has been more commonly used. Even though the CRPD was ratified in 2008 in Sweden, it is only recently that anti-discrimination and human rights frameworks have begun to influence policy discourse and the disability movement's activism (Sépulchre & Lindberg, 2019).

The new concept of 'functional variations' (funktionsvariation) is more controversial. It is not sanctioned by the Board and is mostly used by activists who are inspired by Crip theory (Rydström, 2012). In an interview I conducted with an official working at the Council for Disability Issues, the choice to include the word 'functional variations' was explained as an answer to some disability organisations' wishes for a more inclusive and modern language. According to activists, 'functional variations' as opposed to 'limitations' works as a neutral concept aiming to challenge the negative connotations of disability – instead pointing to the notion of human variation. However, there is no consensus on the meaning and 'correct' use of the word. While some claim that the concept of 'people with functional variations' is interchangeable with 'people with impairments', others claim that the former encompasses all human beings, disabled or not. According to the latter, in order to define disabled people, 'people with norm-breaking functional variations' must be used. Then, it both encompasses the notion that all humans have varying functional abilities – while also emphasising that some have more stigma-related ones and thereby including a structural power dimension (cf. Kafer, 2013).

5.3 Administrative and Political Views

A theme for discussion in interviews with councillors and officials concerned the policy for the Council, and specifically the decision to have representation among a

range of ‘difficulty’ categories, presented in the previous sections. One of the officials explains:

The region has chosen to talk about functionality rather than diagnoses. ‘Difficulty to see’ might be a diabetic with retinal detachment or a person with cataract. Either way, the question is: what needs to be done for things to work out for these persons, regardless of diagnosis? That is how we think. Well, you need good lighting, contrasting, etc., regardless if one has diabetes or eye injury. (Interview, official)

In other words, regardless of diagnosis or impairment the focus lies on the accessibility needs (‘difficulty’). One of the councillors in the focus group believed that this perspective allowed for a ‘broadening of the term disability’.

However, there seemed to be certain difficulties in addressing accessibility considerations in practice when there were competing barriers among different ‘difficulty’ groups. The councillors discussed how technical developments in society which make certain things more accessible for some can mean that for others, they become even less accessible:

Councillor 1: And then there are groups in the disability movement that are very odd, whose needs are hard to cater to, so to speak. For example, electromagnetic hypersensitivity and dental injuries. These two, it is very hard to cater to all their needs, because it is in conflict with societal developments. (...)

Councillor 2: A technical development can actually result in inaccessibility for people who have not used computers, for example. So, it is a challenge not to let developments create new inaccessibility. One usually doesn’t think very much about that, because you think that all development is good. But not for everyone. It depends a bit on where you are on the scale. (Focus group, Councillors)

In other words, the councillors did not seem to understand disability entirely in terms of the gap model which ‘assumes to a utopian extent that the gap between ability and expectation can always be closed’ (Grue, 2015: 39) – in fact, they seemed to regard full accessibility as utopian. But it was also evident that they would not simply state that accessibility cannot be accommodated for all – something that could easily be interpreted as discriminatory or inhumane. However, they did take measures to meet these ‘outlier’ organisations which did not have seats in the Council, in order to answer their pleas to have their voices heard. But they did not see this as collaborative governance:

Councillor 1: This is a tough balancing act. There are 11 seats in the Council – how many can there be for it to be a Council?

Councillor 2: And when is it constructive? Because if there are 30 seats then maybe it is not.

Councillor 1: No, then it’s not a Council, but more of an information meeting. The idea is that we should be able to have a dialogue and do something together; the disability movement and policy-makers. And then one has to weigh in those aspects, that it becomes constructive.

The administrative terminology around disability can thereby, on the one hand, be understood as rhetorical, emphasising the need to use an inclusive and non-derogatory

language and including activist concepts such as ‘functional variations’. On the other hand, this rhetoric is not always reflected in practice, as the politicians’ views on what counts as reasonable accessibility excludes certain types of accessibility needs. Furthermore, the organisation of the Council is based on certain definitions of collaborative governance, where the number of seats determines opportunities to have constructive dialogues, compared to simply information sharing.

5.4 Challenges with Collaboration

A second theme in the interviews and focus groups concerned various challenges with collaborating between different types of disability rights organisations. Firstly, there were difficulties within umbrella organisations. The main regional umbrella organisation Funktionsrätt Västra Götaland, introduced earlier, showcased a variety among its members when considering different patient and impairment groups. A majority comprised diagnosis-specific organisations but there were also a few broader disability rights organisations. There seemed to be some division among these two different organisation types, as described by an interviewee from a patient organisation, the Psoriasis Association Västra Götaland:

We haven't gotten involved in [the umbrella] that much. We have tried though. A couple of years ago I was a bit more active there – but we are a bit on the side, since they are organised according to the five criteria [difficulties] and we do not really fit into any of those. We think that there should be a medical group, or diagnostic group, or whatever you want to call it. That is the opinion of the digestive and gastrointestinal, diabetic and those diagnoses as well. But I feel that our issues drown in the bigger issues, so to speak. There are groups with bigger issues, like physical accessibility and communication problems like the hearing and visually impaired have – those issues might be a bit easier to handle for [the umbrella] than ours.

Here, the distinction between ‘condition’-specific and broader disability rights organisations becomes visible. Several other organisations also mentioned their struggles to be heard in the umbrella. Some of them have stayed passive members, like the Psoriasis Association, while others have started new organisations, such as NSPHiG, a network for mental health organisations in the region, organised within a national umbrella, the National Partnership for Mental Health (NSPH). This in turn has led to new tensions within the movement, as some organisations, among them Funktionsrätt Västra Götaland, felt that this has led to fragmentation and increased competition (cf. Hugemark & Roman, 2007).

For NSPHiG and its members, on the other hand, being included in the umbrella would mean a better platform for raising mental health issues specifically, as explained by a representative that I interviewed. The interviewee recounted other challenges with collaborating with the umbrella, based on the way they worked. NSPHiG differed in advocacy methods since they worked in a project-based manner, for example implementing peer support and developing new methods in the psychiatric care – ‘advocacy in practice’. The interviewee said that ‘we do not change anything by simply pointing fingers and telling [the region] how wrong they do things’. Instead, they aimed to

present concrete solutions to the problems that their members experienced (cf. Markström & Karlsson, 2013). However, they had been unsuccessful in being appointed by the umbrella to become a representative in the Council for Disability Issues, and felt that it was due to their organisational differences as well as representing members with psychiatric diagnoses rather than ‘traditional’ impairments.

Interestingly, a so-called traditional disability organisation DHR Göteborg, representing people with mobility impairments in the city of Göteborg, had chosen not to become a member of the umbrella. The interviewed representative explained that they have worked hard for the past 16 years to remove disability policies from the health care domain. They believed that the umbrella, by having many patient organisations as members, represented a more medically-oriented ideology. A representative from DHR Västra Götaland, the organisation’s regional branch, added that their organisation was different from patient organisations since DHR ‘does not work with diagnoses, but a lot more with society’ (cf. Hugemark & Roman, 2007; Hughes, 2009).

DHR’s youth organisation Unga Rörelsehindrade Göteborg went even further:

Representative 1: We have left the diagnosis part and instead joined the greater struggle. (...)

Representative 2: We think in new ways and go to places where we are not expected, like West Pride [a local LGBTQ rights festival]. (...) And also, that there is more discussion about other minorities’ rights in society – that our rights are as important as theirs.

Representative 1: We also attend, for example, feminist groups, to show that functionality is often forgotten even where intersectionality is discussed. We actively choose to be in those circles, because we expect solidarity, so that they can come to us as well. (Group interview, Unga Rörelsehindrade Göteborg)

In their view, disability issues are not only societal as opposed to medical issues, but also part of human rights on a broader spectrum shared with other minorities. They worked for a shared movement, which parallels some parts of the broader disability movement worldwide, particularly the American minority model (Charlton, 1997). Rather than collaborating only with traditional disability organisations, they also collaborated with other types of organisations that were not disability-related, like feminist and LGBTQ rights organisations (cf. Beresford & Branfield, 2011).

5.5 Competing Disability Definitions

The organisational boundaries could also be seen to be reflected in language and identification among organisations and representatives. There did not seem to be any clear-cut boundaries around disability definitions, either among organisations representing similar impairment groups, or between different types of impairment groups. For instance, Unga Rörelsehindrade Göteborg used the term ‘functional variations’ as part of, in their own view, a more radical agenda compared to organisations representing disabled adults. An example of the latter was Brain Power Västra Götaland, a regional branch of the Swedish organisation for people with acquired

brain injury, whose representative felt that the term ‘functional variations’ did not acknowledge ‘a vulnerable group that doesn’t fit into society’ (cf. Sherry, 2019).

To avoid such problems, ‘people with *norm-breaking* functional variations’ could be used according to Unga Rörelsehindrade Göteborg, but it was also felt to be an overly complicated term for everyday usage. Instead ‘people with functional variations’ could be seen as a compromise. It worked both in everyday usage and was relatively easy to understand, while it also embraced a norm-critical understanding of bodily normality. The organisation’s relationship to the wider feminist movement and queer activism discussed earlier was visible in this reasoning as well (cf. García-Santesmases Fernández, Vergés Bosch & Almeda Samaranch, 2017).

An alternative perspective was given by one of the local diabetes organisations whose representative wrote: ‘we don’t see ourselves as disabled’ (survey answer). However, a representative from another local branch had a seat on the Council on Disability Issues for the group defined by ‘difficulty to tolerate certain substances’, and the organisation was a member of Funktionsrätt Västra Götaland, the umbrella body. In other words, there was not always a shared/consistent view – even within the same organisation. A possible reason was the strategic purpose to be part of a network which had seats at the policy-makers’ table.

Another example of not identifying as disabled came from an organisation for cancer patients:

Yes, [cancer] can definitely turn into a disability but very few would categorise themselves as disabled. The illness causes us pain and we have side-effects, that’s how we put it. [...] Maybe there’s a stigma to the word disability. To be categorised as handicapped – while people with blood cancer are not handicapped, even though they are not fully functioning either ... I don’t know, but I don’t think in such categories and titles that much. (Interview, the Blood Cancer Association West)

This example shows an established conflict within the disability movement concerning the view of disability as *not* illness, which simultaneously alienates people with chronic illnesses (Wendell, 2013). Essentially, as this person explained in the interview, both groups experience impairment effects, but the identification differs from the more social movement type of disability organisation to the medically and health care-oriented patient organisation (cf. Grue, 2014).

The dance company Spinn represented an outsider’s position as they were not primarily an advocacy organisation. Similar to Passalen, the activity-based organisation aimed at children with ‘functional variations’ mentioned earlier, Spinn worked with disability rights and representation in culture through their integrated dance productions, that is, where disabled and non-disabled dancers work together. They had experienced difficulties in becoming part of the traditional disability movement:

The political correctness surrounding disabilities and not least all the words; which ones to use, how to address ... Like, what if I use the wrong word or offend somebody? [...] The disability movement has a lot to learn, not to scare people off by disciplining the language – that’s not a justifiable way ahead. Because then people will isolate themselves in small reserves and sects and then there is no development. (Interview, Spinn dance company)

The two interviewed representatives explained that to welcome people irrespective of dis/ability they used the term ‘functional differences’ (funktionsskillnader) – a less-used version of the ‘functional variations’ term introduced earlier.

In the interview with Spinn, language and organisational perspectives intertwined. The disability movement was not only defined by impairment categorisations, but also by organisation types. Spinn challenged this in two ways: firstly, by being an integrated dance company, including both non-disabled and disabled dancers, and secondly, by not primarily focusing on advocacy activities. They argued that their mere existence challenged societal norms of embodiment, dis/ability and representation in the cultural sphere, leading to side-effects of disability advocacy (cf. DeMirjyn, 2018). Furthermore, their organisation type challenged impairment categorisations within the disability movement.

5.6 Patients’ Rights or Human Rights?

The differences in language and ideology were further discussed in relation to opportunities for influencing regional policies on human rights. When asked about their experiences of influencing the Council, which was located within the Committee on Human Rights, one patient organisation responded:

When you have the kind of organisation that we have, a patient organisation, then some issues don't really fit in, because we don't have that kind of all-encompassing ... I mean, our main objective is to inform our members and the public about glaucoma, and then try to have contact with the eye health care and influence them to some extent. (Interview, the Glaucoma Association Gothenburg)

According to the interviewee, their organisation did not try to influence human rights policies, instead focusing on health care services.

Similarly, an organisation for people with migraines reasoned:

To us it's about good doctors and good medicines, basically. So far. And good research aiming to get rid of [migraine], so that we can come to terms with why it appears, and remove the misery. Secondly, medicines that prevent it. (Interview, the Migraine Association in Västra Götaland)

These organisations have therefore chosen not to engage with the Committee or the Council. The Migraine Association’s representative explained that they focused on arranging lectures with doctors and researchers for their members to learn more about migraine, medicines, and on how to live a good life despite the diagnosis. These organisations worked mostly on what Sherry (2016) has termed ‘impairment literacy’, which can be very important for individuals who are struggling with their impairment effects (see also Sherry, 2019).

A potential problem resulting from these differences among organisation types concerns representation (cf. Hugemark & Roman, 2007). A representative of the ‘difficulty to hear’ category in the Council for Disability Issues explained:

In principle, I have always felt that I was in the wrong place in this council, even though we [the Deaf community] believe that the disability movement is fantastic and meaningful in society, and we also

have members who have difficulties moving, seeing, tolerating certain substances, interpreting and processing information, and so on. However, if I got the choice, I would rather be in the Minority Council, since they have language, culture and identity as their main issues, just like Deaf and sign language users fight for in society. But we came to the Handicap Council already in 1999 when it started, since society see us, Deaf people as having an impairment. [...] But still, Deaf people don't see themselves as disabled at all. (E-mail follow-up interview, representative in the Council)

The representative discussed an established division among the disability movement and the Deaf movement, based on which identity is seen as most central for rights advocacy: disability or culture (see Loce-Mandes, 2019 for a recent example).

A similar difference could be seen between different organisations related to hearing impairment. An interviewed representative of the Swedish Association for Deafblind West explained that they advocated for both social and medical issues, such as parents' right to sign language education, as well as the right to adequate health care. In their view, The Swedish Association for Children with Cochlear Implant or Hearing Aids focused almost exclusively on the right to medical aids and services, thereby representing a more medical model understanding of disability, making constructive collaboration difficult.

6. Inclusion for Whom and On What Terms?

In this article, I have analysed two specific issues relating to a case study of the Council on Disability Issues in West Sweden. First, I analysed how disability definitions in the policies for collaborative governance influenced disability organisations' advocacy work and possibilities for participation. Second, I explored how disability was conceptualised among a range of disability organisations, and what consequences different organisations' conceptualisations had for their collaborations with each other and with the Council.

6.1 The Relationship Between Policy and Practice

To contextualise, the Council is a formally structured way of institutionalising disability rights organisations' influence in policy-making through the specific process of collaborative governance. This is in fact mandated by the UN CRPD as well as in national and local governments' policies. But considering how the Council is regulated, specifically in relation to disability definitions, offers a somewhat different picture. Firstly, the administrative definition of eligible organisations, that is, democratically structured non-profit membership organisations with a certain number of members across a certain number of municipalities in the region, in fact excludes other types of organisations that work with disability rights.

Secondly, although the 11 member organisations in the Council are not elected as representatives of their organisations, but as representatives of five groups of 'difficulties', and eligible organisations are defined as 'organisations representing people with impairments/functional variations or patients', confusion and insecurity remain as to which organisations are relevant in practice. As the focus group

with the politicians revealed, they did not consider certain ‘fringe’ organisations as entirely relevant, since their access needs were seen as too different compared to the issues that were usually discussed in the Council – and sometimes also discussed as counter to normative societal developments. Still, such organisations were invited to separate meetings to ‘hear them out’.

These two aspects can be understood as ordinary-political misrepresentation (Fraser, 2008), meaning that the decision-rules of deliberations did not encompass all concerned, that is, the ‘how’ of justice. But it also relates to misframing and the ‘what’ of justice, namely what type of issues the organisations were invited to advocate for. Indirectly, the councillors’ arguments also conveyed a view about who counts as a ‘deserving’ disabled person with legitimate and reasonable accessibility needs. This was not so much dependent on a specific diagnosis but on the specific claims/needs – a discourse similar to the one on the ‘deserving poor’ (Ingram & Schneider, 2005). It was also visible how the policies had rhetorical aims to include disability rights but that in practice it was not made fully possible within the available structures (see also Barnes, 2007; Morris, 2011).

6.2 Tensions Among Disability Rights Organisations

Similar processes were evident in the collaborations – or lack thereof – among the interviewed disability rights organisations. The historically strong position of the main umbrella organisation in the region posed difficulties when other types of organisations would like to participate, since the umbrella appointed many of the representatives to the Council. Some of the interviewed organisations also discussed not feeling represented by the umbrella organisation because of the type of issues that were most often the focus of advocacy (cf. Näslund, Sjöström & Markström, 2019). Here the long-standing issue of who and how disability representation should be done came to the fore, most notably between broader disability rights organisations and more narrowly focused patient organisations (cf. Hughes, 2009). But these divisions were not straightforward, since representatives from similar organisations sometimes express competing views of how their access needs fit into a broader disability rights agenda.

Similarly, there are also examples of tendencies towards generational divides, when organisations representing young disabled people, at least to some degree, appear to be more interested in collaborating with other types of social justice organisations than with those focused upon disability. The position of the few organisations working in a manner that was different from traditional advocacy, for example, the cultural and activity-based organisations, illuminates yet another type of division which can have consequences for opportunities in formal policy influence. Thus, it can be argued that the umbrella organisation was not representative of the ‘total population’ of organisations representing disabled people in the region.

With these aspects in mind, we can see how issues around misframing are also evident among ‘all concerned’ (Fraser, 2008) – that is, among disability organisations. There are ongoing discussions and tensions about the ‘who’ as well as the ‘how’

of justice and representation. This is a level of misframing which has both historical roots in the disability and patient movements, and which was influenced by the current administrative regulations and definitions of eligible organisations. These 'meta-political' aspects of injustice, then, are actually not only decided upon by 'powerful elites', in the words of Fraser, but are also upheld by those concerned (those facing the injustice). She thereby raises the important issue of difficulties around equal representation in civil society. It is clear that the focus in some organisations on 'impairment literacy' based on an 'illness narrative' (Sherry, 2019) compared to a more social model-oriented disability rights advocacy, is creating tensions (Thomas, 2007) – not least with regards to the 'what' of justice claims (Fraser, 2008).

As empirical research has shown, however, umbrella organisations encompassing a wide range of disability and patient organisations employ more pragmatic approaches to their advocacy discourse, not least in relation to what they think is expected of them in the eyes of policy-makers (Grue, 2009). However, as both Thomas (2007) and Grue (2014) highlight, impairment effects are culturally and politically infused, and thus stigma may be more attached to the identity of 'disabled' compared to being 'ill'. There is thus another strategic purpose of using a more rights-based rhetoric in collaborative governance, such as in the Council on Disability Issues, which sits in the Section on Human Rights (cf. Grue, 2014).

6.3 Future Directions

Although impairment-specific organisations may not be as politically focused, they have an important role in fostering 'impairment literacy' and in the long run, for their members, allowing them to be better informed about their impairment. Experiencing community with others in similar situations, can lay the groundwork for moving beyond an individual focus to a broader political struggle for inclusion and access (Sherry, 2016). This suggestion is in line with some disability scholars' argument that impairment, which is negatively valued socially, cannot form the basis of disabled identity (Shakespeare, 2013). At the same time, social model-based activism, although it has been powerful and motivating for fighting oppression and removing the problem from the individual to society, still risks rendering disabled people 'as victims rather than agents' (ibid.:106). A possible solution would be to speak of accessibility and specific rights or issues rather than disability (cf. Beresford & Branfield, 2011). Instead of defining a limited set of impairments (or 'difficulties' in this case) and assigning representatives on such basis, themes or issues concerning specific accessibility needs could be an alternative. Thereby, any individual's voice can be heard regardless of impairment type or whether they define themselves as disabled. Arguing over disability terminology would then be redundant, i.e. the 'who' of justice becomes more open and inclusive.

Not having to identify with a disability identity, an organisation or a movement, but being able to simply voice an opinion on issues that one is affected by, may encourage more people – or at least other people – to exercise their citizenship in collaborative governance systems. Making collaborative governance truly collaborative requires

significant efforts and resources that build on the needs and knowledge of the people concerned rather than on institutional structures (Beresford & Branfield, 2011) – thereby challenging the long tradition of a specific type of collaborative governance in the Swedish context. This may not least be more inclusive to activists who for reasons to do with life circumstances and impairment-effects cannot participate in traditional advocacy (Chowaniec-Rylke, 2019; Crow & Merchant, 2019).

More than anything, however, the need for institutionalising councils on disability, or any other ‘minority’ issue, points to the fact that disabled people are not included in general policy-making – in Fraser’s (2008) words, a meta-political injustice. In fact, social policy has constructed disability as deficit and in need of institutional interventions rather than systemic societal change (Oliver, 1990). Herein lies the structural power dimension of ableism which makes it possible for non-disabled politicians and officials to decide on definitions and criteria for what counts as disability and legitimate claims. Thus, collaborative governance with inclusive language (‘difficulties’ rather than ‘impairments’) is still inherently exclusionary if called a council on ‘disability issues’ – and does not necessarily lead to more inclusion on a broader societal level. However, local councils can be meaningful for individuals in other important ways.

Coming to terms with unequal participation on a structural level will require Fraser’s (2008) transformational approach; changing the system rather than making changes within it. The question remains who is to advocate for such a change when many organisations already struggle to make their voices heard and to assemble the resources needed to do so (Beresford, 2010). It is improbable that politicians or officials will be the driving forces for such change, as it would likely make their work more complicated and demanding (or at least be thought of as such). A broader approach to both citizenship and policy implementation is needed, where inaccessibility and discrimination are not seen as isolated issues concerning only disabled people (cf. Lawson & Beckett, 2020). Such a social justice approach ought to comprise not only political representation in isolation, but also in relation to economic redistribution and cultural recognition (Mladenov, 2017). Without adequate financial security and without fair representation, disabled people will most probably continue to ‘challenge oppressive policy regimes’ (Kelly, 2010)

This, then, is the recurring dilemma for the disability movement: how to succeed in mainstreaming disability issues, while at the same time detaching from the particularised and potentially stigmatising disability identity that many disabled people avoid. Herein lies the challenge for both current and future activists and organisations, namely to balance ideology, strategy and solidarity within the disability movement – but also beyond it (cf. Graham, 2019; McKenna, Peters & Moth, 2019). Although there are examples of divisions in disability movements based on diversity and complexity in identities, there are also more optimistic visions of how increased inclusivity ‘will allow for more disabled people to relate to and identify with the movement’ (Kelly, 2010,).

7. Conclusion

This research has highlighted the processual relationship between governmental administrative regulations, language use and civil society organisation (cf. Williams, 2018). There is a lack of shared discourse on the ‘what’, ‘who’ and ‘how’ of justice, leading to unequal participation and what Fraser (2008) calls abnormal justice. It could indeed be argued that all organisations, including diagnosis-specific ones, have a stake in the broader struggle for social and economic equality – citizenship – that disability rights encompass (cf. Sherry, 2019). Essentially, the right to good and equal health care is part of the CRPD – possibly also during a temporary period in life (Barnes & Cotterell, 2011). However, stigma may lead to avoidance of a disability identity, creating problems for identity politics, which, irrespective of organisation type, is essential to all organisations – albeit on different grounds and with various strategic and ideological purposes. Based on this study’s results and with inspiration from the arguments put forward by the many important previous studies cited, I argue that collaborative governance processes must build upon shared experiences of structural inequalities among various groups, ensuing from disablement as well as other types of marginalisation – but in the next step focusing on *shared issues* rather than identities. This could be an approach worth experimenting with on local levels to build trust among movements, activists and policy-makers, for future larger-scale transformational approaches to inclusive policy-making – and, in the end, more equal communities and societies.

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NOTES

- *1. Based on a social model approach I use the term ‘disabled people’ to emphasise the political position of people with impairments in a disabling and ableist society (Campbell, 2009; Oliver, 1990).
- *2. Impairment has traditionally not been in focus in the social model of disability, but I find it important to highlight ‘impairment effects’ when they are relevant, that is, the physical, sensory, intellectual or emotional impacts from one’s embodied functioning – but recognising that they are also socially and culturally constructed (Thomas, 2007: 135f).
- *3. The 11th organisation was unfortunately not able to make it to the focus group as planned.

- *4. The reason behind this somewhat unusual categorisation is explained in a publication about the work of the first Handicap Committee: 'we tried to avoid value-laden words and etiquettes that easily become stereotypical', and furthermore, they aimed to broaden the perspective from certain diagnoses or specialised organisations (Handikappkommittén, 2010: 18).
- *5. There is also a smaller regional umbrella, Funktionsrätt Skaraborg, which receives funding.

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