User councils for disabled people in Norway – from reactive to proactive?

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ABSTRACT
User councils act as advisory bodies for the agencies with which they are associated. This article is based on interviews with user participants and agency representatives from a sample of user councils in Norway. The main question raised is how user participation functions in user councils. In general, the findings show that among the user councils there are active discussions, most of the user informants feel that they are respected as equal partners and that they are taken seriously. However, the work is characterized by representatives from the agencies taking the initiative to raise issues and the user representatives responding to these initiatives, and in that way the user participants function reactively. Most of the informants from the agencies want the user representatives to be more active and critical. This raises concerns about how user participants can be more proactive. Finally, some prerequisites for improving the functioning of user councils are discussed.

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Introduction

User involvement and participation has become more widespread in the welfare sector. In Norway it is common to differentiate between user participation at an individual level and at a systemic or collective level (Alm Andreassen 1991; St. meld. nr. 34 1996–1997). The individual level refers to the involvement of individual service users in their own use of services. The systemic level includes participation beyond the individual use of services. User councils are one form of participation at the systemic level and act as advisory bodies for the institutions or organizations (welfare agencies) with which they are associated. In some of the British user involvement literature, such deliberative forums, established through agency-led initiatives, are criticized for being steered by the agencies and for co-opting and disempowering user participants (Cowden and Singh 2007; Beresford 2012). Some authors also point out that agencies question the representativeness of user participants (Beresford and Campbell 1994; Beresford and Branfield 2012; Carr 2012). Further on, they mean that user organizations must consider this type of representation versus alternative uses of resources. On the basis of their role as activists in user movements, Beresford and Campbell (1994, 324) make a fundamental statement on this issue:

A lesson many of us have learned from our own movements may offer a helpful last word on representation here. It makes sense to spend more of our energy participating in our own initiatives rather than being represented in service systems. That is where the real promise of participation, empowerment and our representation in society lies.

Is there no hope for improving such forums for user participation? This article is based on a study of a sample of user councils associated with institutions and organizations from different parts of the
welfare sector in a region (county) in Norway (see Andersen 2011 for further elaboration). The study is based on interviews with user participants from the Norwegian Federation of Organizations of Disabled People (FFO) and representatives from the agencies with which the user councils are associated. FFO at the regional level took the initiative to the study because they wanted more knowledge on how the user councils function and what the experiences are both from the user participants’ and the agencies’ point of view. I made an application for a research project in cooperation with FFO and the project was funded by the Norwegian Directorate of Health. The purpose of the study was to gain more knowledge of how user participation in user councils functions, and how the representatives from the agencies and the user representatives evaluate the usefulness of the councils. In this article, three main questions will be discussed. First, how well do the user councils function, as evaluated by the user participants and the agency representatives? Second, what are some of the common features, between the various user councils, in the way they function? And, finally, what are possible improvements to the way the user councils function that would increase the influence of user participants as well as the overall functioning of the councils?

The FFO is an umbrella group of member organizations focused on more specific impairments or chronic diseases. At the national level FFO has 71 member organizations and is the largest umbrella group for organizations of disabled people and people with chronic diseases in Norway. FFO is an advocacy organization, and its activities are directed towards political organs at all levels, public administration and user councils in which the organization has participants. In addition to the advocacy work the organization creates arenas and meeting places where the member organizations can cooperate in common fields of interest. The umbrella organization chooses representatives to user councils at the regional and local levels, and also ensures that these representatives have at least a basic education in being user participants at the systemic level. The agencies that the user councils are connected to are expected to give the user participants information about the welfare sector and the agencies in question. This includes information about the tasks, responsibilities and organizational structure of the agencies.

**Theoretical perspectives**

According to Barnes et al. (2004, 93–94), analysis of action which seeks to enable a dialogue between the state and its citizens has often distinguished between ‘top-down’ initiatives from within state agencies to consult with or involve citizens, and autonomous action among groups of citizens who seek to articulate and give expression to shared experience.

Public participation initiated from within public agencies draws on theories of governance and public policy making, while autonomous action among groups of citizens has been theorized in terms of new social movements and the politics of identity (see Barnes et al. 2004 for further elaboration).

User participation at the systemic level in the form of user councils is a top-down initiative. Establishing user participation at the systemic level is a statutory duty for most of the public agencies and service providers in the Norwegian welfare sector. The reasons for user participation at the collective level may be twofold: democratic and instrumental (usefulness).

The democratic approach is concerned with the involved parties’ right to be heard, and the right to participate is intended to provide opportunities to influence decision-making. This is in line with the traditional corporate pluralist model in the Nordic welfare states (Pierre and Peters 2000). There is an emphasis on ‘the importance of creating opportunities for people excluded from decision-making to become empowered and influence decisions reached’ (Barnes et al. 2004, 93). It is likely that the democratic model of participation will also work on a wider agenda, and the ‘goals will thus reside in the wider avenues of citizenship in which oppression and exclusion are experienced’ (Braye 2000, 19). This suggests that participation can be regarded as a ‘school in democracy’, with the intention to both increase users’ engagement and influence towards a single agency and their engagement as citizens in more general issues in society (Hultqvist and Salonen 2011).
The instrumental approach is concerned with participation as a tool for making better decisions and services. This is seen as a means of ‘improving the legitimacy of decisions and enhancing the responsiveness of the services that are provided’ (Barnes et al. 2004, 93). This approach does not attempt to represent the interests of people who are disabled, but rather to present information from actual users of services (Alm Andreassen 2004). Disabled people and their organizations have a competence (experience-based knowledge) that public authorities and the service providers require to take into account to meet their clients’ needs. Participation is a means to develop the quality of the services provided. The two approaches are often intertwined and function concurrently. Further, regardless of the intended reasons for user participation, the ultimate, shared purpose is that it should have a positive impact on the agencies and service providers that establish user participation bodies.

The democratic and instrumental approaches lead to two conflicting ways of thinking about representation (Alm Andreassen 2009, 153). This can result in disputes that create representation problems. Democratic representation (from the democratic approach) means that there are interests that shall be represented. The user organizations choose their representatives, and the representatives are responsible to their organizations. According to Barnes (1999, 86), ‘users are often more effective participants if they have the support of others and can link into shared and common experiences, rather than speak solely from personal experience’. She stresses the significance of shared identity as a basis for collective action (Barnes 1999, 73). Statistical representation (from the instrumental approach) means that user representatives should be a representative selection taken from among the user groups of the respective services. The intention of such representation is to acquire knowledge of the users’ situations and of their experiences with the services delivered. Sometimes these two ways of thinking about representation merge relatively well. Representatives from the user organizations may be active users of the services delivered, or they may represent organizations that have active users as members. In other contexts there are not such close connections between the democratic and statistical representation, and then the tension between them is more obvious. In these cases one may change the method of choosing representatives or one may use satisfaction surveys and other means to get the valuations from the core users, as a supplement to the user representation.

User councils are consultative and advisory bodies connected to an agency (organization or institution) or related to a wider area or sector. Unlike satisfaction surveys and hearings, which are one-way communication, the user council represents two-way communication between user representatives and representatives from the agencies the council is connected to. Ideally, user councils promote dialogue and collaboration, and function as deliberative forums (Alm Andreassen 2009). An important prerequisite is that the councils are constructed in a way that fosters a balanced relationship between the parties and avoids strengthening asymmetric relations. The advisory role is also more comprehensive than simply providing systematic feedback of the users’ experiences of the services. It also includes providing advice on what the agencies should do based on such information.

Leaving the reasons for user participation, we have to consider how the user participation actually function. How do the user councils function in practise? I will introduce three perspectives or ways of analysing this: a rational perspective, a symbolic and a perspective of co-option. As mentioned earlier, the user councils are intended to have a practical impact on the agencies they are connected to, with both democratic and instrumental approaches. I will refer to this intention as a rational perspective. This means that the user council is understood as useful for all parties involved. This perspective can be in accordance with an instrumental approach in organizational theory (e.g. Christensen et. al. 2007). However, in practice the user councils may function otherwise. The user councils may have more symbolic, legitimizing functions, for example, providing window dressing for the agencies, but with no real impact in practise. This is referred to as the symbolic perspective, and can also correspond with a myth perspective within an institutional approach as defined in organizational theory (Christensen et. al. 2007). The third perspective is co-option. According to Selznick (1984/1949, 13) co-
option is ‘the process of absorbing new elements into the leadership or policy-determining structure of an organization as a means of averting threats to its stability or existence’. The leaders of agencies may try to legitimize their actions by explaining their plans to the user councils and convincing them to lend their support. In this way, members of the user councils and the organizations they represent can be made co-responsible for the agencies’ decisions, which will help to silence critics. In Selznick’s words, this means ‘that what is shared is the responsibility for power rather than power itself’ (Selznick 1984/1949, 14). Thus, co-option implies a risk that independent organizations could be incorporated into the establishment, resulting in a loss of power and autonomy for the former (Hultqvist and Salonen 2011).

From a user involvement viewpoint, the function of user councils either as symbolic or co-optioned has to be considered as malfunctions of user participation. These possible malfunctions of user participation have been a concern of researchers in the field. Barnes and Cotterell (2012, xxi) claim that there is an important tension between ‘user-led and officially determined participation initiatives’. In an earlier work Barnes (1999, 86) addresses both the possible threat and opportunity: ‘Whilst participation carries the dangers of incorporation, there is also evidence of transformation taking place both in the processes of governance and the service models emerging from dialogue between users and producers’.

Beresford (2012, 31) illustrates the different perspectives by referring to the ambiguity of user involvement:

Participatory initiatives and arrangements can result in the redistribution of power, changed, more equal relationships and the creation of opportunities for influence. Equally they often also serve in practice as a means of keeping power from people and giving a false impression of its transfer. This is frequently articulated in service users’ complaints about user involvement being used to ‘rubber stamp’, ‘tick boxes’, ‘tokenize’ and ‘incorporate’ them. Participatory schemes can be used for these two conflicting purposes according to whether their initiators aim to hold on to power, or share it.

This creates a number of dilemmas for user groups, and two tensions Barnes (1999) mentions which are relevant in our context are the danger of ‘consultation overload’ and of being purely reactive. Consultation overload may be a result of user involvement being more widespread and user representatives being unable to manage all the involvement in a proper manner. This may lead to: ‘The danger of becoming reactive to official agendas, rather than determining their own priorities for action’, and result in a situation where ‘constantly responding to the agendas of officials could take up all the limited resources of groups’ (Barnes 1999, 86).

If we understand reactive behaviour as adjusting to a situation or acting in a more passive manner, such as responding to issues and propositions from others, we can contrast that with proactive behaviour. Crant (2000, 436) defines proactive behaviour as ‘taking initiative in improving current circumstances or creating new ones; it involves challenging the status quo rather than passively adapting to present conditions’. In our context, proactive behaviour from the user participants encompasses taking an active role in raising issues, advocating on behalf of the users, being a critical user voice, collecting information and knowledge of the field the agency operates in and so on.

Methodology

This study deals with a sample of user councils in Oppland County in Norway. The population of user councils was limited to councils established as advisory organs for agencies or welfare areas on a more permanent basis, therefore not including ad hoc groups such as project groups, or organs discussing single cases (concerning individual users).

From an overview of the user councils with user participants from the FFO I made a sample of 12 user councils. The criteria for making the sample were to include a range of agencies (see Andersen 2011 for further details). The chosen agencies cover institutions and organizations from different parts of the welfare sector, such as hospitals, psychiatry, rehabilitation, welfare administration and
councils for disabled people in the municipalities. Both public and private institutions are represented.

Relevant documents from the institutions have been studied to gain some actual information about the agencies and user councils, but the main empirical data have been obtained through interviews with user participants from the FFO and representatives from the agencies with which the user councils are associated. The representative from each agency is either the leader of the agency or the individual who represents the leader in council meetings. In total, 16 user participants and 10 representatives from the agencies have been interviewed. I conducted the interviews in the spring 2011. The duration of the interviews were from 45 minutes to 2 hours, most of them around 1 hour. The representatives from the agencies were interviewed in their office, and the user participants were interviewed in different places, chosen by themselves.

The main goals for the interviews were to get the informants’ evaluations of how the user councils function and their usefulness, what kind of influence the user representatives have and what kind of barriers to influence exist. An important theme was also to find out their suggestions on how to improve the way the user councils function. I used a semi-structured interview guide with a list of themes and questions to be asked and possibilities to have following up questions (Kvale 2001).

I used a digital voice recorder in the interviews and then transcribed them, for the most part, word for word, although topics irrelevant to the study were excluded. In the analyses the informants’ answers are grouped under the different topics, and answers belonging to other topics have been moved to the right topics. The coded categories were partly decided in forehand and partly developed through the analyses. The analyses of the data also made it possible to discover some common features in the way the user councils function, and to derive from the material some potential improvements.

The user councils studied may not be representative of how the user councils function in general. Firstly, there may be some existing councils where no user representatives from FFO are selected. They are not included in the population. Secondly, I cannot rule out that the selected user councils are among the best functioning, even though this is not a criterion for the selection of the councils. I will return to the possible implications of this later.

What are the characteristics of the user councils and how do they function?

Characteristics and responsibilities of the user councils

There are two types of user councils in the sample. The first is a pure user council consisting of user participants as the only full members, along with the representative(s) of the agency, who can attend meetings but only with the right to speak. In this type of council one of the user participants is the leader. The second type of user council is referred to here as a mixed council, and is composed of a mix of user participants and representative(s) from the agency who all have full rights in the council. Usually the lead representative from the agency is the leader of this type of council.

The user councils function in an advisory capacity for the management groups of the agencies. Some of the agencies have boards of directors, and the user councils have similar advisory capacities towards such boards. In addition, a representative from the user council may have the right to attend and speak in board meetings, although not the right to vote.

Extracted from documents describing the councils and the interviews of the actors, the user councils seem to have the following responsibilities and limitations:

1. Be informed about the purpose and responsibilities of the agency;
2. Be an arena for dialogue and cooperation between the users and the agency;
3. Contribute to securing the interests of the users;
4. Contribute to user participation in reality;
Contribute to securing the quality of the services and to developing the services;

The user participants may, on their own initiative, present issues concerning the users;

The councils cannot undertake case management of individual users’ cases.

The user councils get material from the agencies to comment on, such as budgets and budget cuts, plans, cases of building or reconstruction, quality measurement, satisfaction surveys and so on.

Most of the councils have a formalized way of functioning, including written summonses, written agendas and summaries from the meetings. The user participants also get compensation for travel expenses and for council meetings.

In general, the user councils in the sample meet important formal requirements for advisory bodies. The formalities make the basis of developing a balanced relationship between the user representatives and the representatives from the agencies, and creating two-way communication between the parties. But, how does it actually function in practice?

The user participants feel they are taken seriously

The general picture is that there are active discussions in the council meetings, and most of the user informants feel that they are respected as equal partners. Most of the user informants also express that they are taken seriously, and they declare that their main function is to be watchdogs for user interests. More specifically, this role includes making the problems and needs of the users more visible, as well as contributing to increasing quality of services. One of the user informants expresses it like this:

We are watchdogs. We always think of what is the best for the patients [...] I’m quite satisfied with the job the user council does, and it is not a waste of time and resources. I leave the meetings with a feeling of having achieved something [...] We are respected and heard, at least as partners in discussion – we are deemed important enough to be included in discussions. We feel that we are in a position to make some difference. We are taken seriously.

The user participants also emphasize that they feel that their experience-based knowledge is increasingly treated as equal to professional knowledge. Moreover, they point out, as an indication of being taken seriously, that the leader from the agency attends the meetings of the user councils and also that other representatives from the agency sometimes attend the meetings and provide information about and discuss various aspects of the services.

This is a more positive picture of the functioning of user participation than the literature mentioned earlier puts forward. For instance, in a study conducted by Simmons and Birchall (2005, 276), they conclude that the user participants felt that the decision-makers did not listen to them. This had two meanings: they did not participate in the meetings or, if they attended meetings, they showed no inclination to take into account what users said.

However, there is more uncertainty about the ultimate influence of the user councils on the decisions made by the institutions at different levels. The user informants had problems recounting concrete examples of decisions that they have had a decisive influence on. As one of the user participants says:

It is difficult to point at a concrete issue. We have influence at all levels, but I can’t mention a case where all the others have thought differently and we obtained a breakthrough for something. It is difficult to measure, it is an approach. If we hadn’t been there, what would have happened then? [...] It takes time to bring about things.

At the same time, some of the most experienced user participants had felt a slow change in attitudes over a period of time. The climate of user involvement has definitely changed in a more positive direction, according to the user participants.

Even though the user participants feel that they are respected and taken seriously, it does not necessarily mean that they act proactively. They may take active part in discussions on issues initiated by the representatives from the agencies, as characterized as a more reactive behaviour (e.g. Barnes 1999).
The user participants can be more proactive

In several of the councils the work is characterized by representatives from the agencies taking the initiative to raise issues and the user representatives responding to these initiatives. In a way, the user participants function reactively. This is probably one of the main reasons for the informants from the agencies believing that the user councils have a limited value. A majority of the informants from the agencies want the user representatives to be more active and critical. As the following quotes illustrate, they argue that user councils would be more effective if user participants were more proactive:

- “The user council is a bit like a ‘Mickey Mouse organization’. I inform and present the cases, and I do not get so much back, the participants are not proactive [...] I wish they were more critical [...] There could have been more ‘devil’s advocates’ among them.
- “I invite input on cases from the user organizations, but it is difficult to get. The user participants could have been more in opposition, but it is a question of what you can expect from the participants.
- “I want more vitality and punch in this. I could wish for a more dynamic user council that could bring changes in our practice.
- “There has been too much harmony. It has been too much praise and I have missed the more critical voice, but I feel that it has become better in the last few years. The user participants do promote cases on their own initiative, the leader takes initiative and challenges the other members. We from the agency are also more active.
- “The more active, the better it is. I would have liked more critique. The participants should be capable to give some fresh and useful feedback.
- “The members are active in discussions, but I wish that they would be more active to promote cases they have gotten from their members in the organizations.

How can we explain that the informants from the agencies want more active and critical user councils? There are at least two possible interpretations of these findings. The first one is that the agency representatives answer in the way ‘they are supposed to’; they answer in a politically correct way that they want more active and critical user participants, but they do not necessarily mean what they are saying. This interpretation can be consistent with a symbolic perspective with a missing link between what they say and what they really mean or how they act. Having an active and well-functioning user council may be regarded as a myth in the agencies’ environment that they have to adapt to, but the adaption may only have an ornamental purpose with no necessary connection to their practice (e.g. Christensen et. al. 2007). I cannot reject this interpretation, but I can question it.

I have not had the opportunity in this study to test if the representatives from the agencies actually adapt for more critical and active user councils, and how they would respond if this happened in practice. But, most of the user representatives have not indicated that the agencies have limited their opportunities to be more active and critical. Several of the user participants also admit that they could be more active, and they do not take enough initiative on behalf of the organizations they represent. Some of them complain that they are short on input from their organizations. To a large extent the user representatives and the informants from the agencies have the same valuation of how the user councils function (see Andersen 2011 for further elaboration).

The second interpretation is that the agency representatives really mean what they say, and it is possible to explain this within a rational perspective. From the agencies’ point of view, the usefulness of the user councils will be related to the possibilities to make better decisions and use the user representatives’ experiences to improve the quality of the services. Based on common sense, it is satisfactory for the service providers to deliver services on which users have positive evaluations (Wistow and Barnes 1993). According to Wistow and Barnes (1993, 292) ‘this is especially the case in health and welfare services which depend heavily on the quality of relationships between users, carers and providers’. It is also reasonable to believe that when the agencies and their representatives spend time and resources on the user councils they are concerned about getting something out of their efforts. It is not sufficient to simply have cosy chats in meetings over coffee. Some of the agency representatives also noted that it is useful to have the user voices as a corrective balance to the professional voices at the agency.
These findings indicate that it is possible to analyse the functioning of the user councils, and the parties’ expectations of how they should function, with a rational perspective. The councils’ usefulness to the parties may be increased by the user participants becoming more active and critical.

As mentioned earlier, it is not possible to conclude that these findings are representative for user councils in general. There are probably other agencies with user councils having a more symbolic or legitimizing role or where the user representatives are co-opted. But, my most important point is that in user councils that are functioning productively, there seems to be leeway for the user representatives to develop a critical-constructive practice and take initiative and be active in different ways, that is, to develop a more proactive behaviour.

Whether the positive trend of user involvement, and particularly the positive attitudes towards user participation at the system level, shall persist will probably depend on whether all parties come to see user involvement as important and useful. This gives rise to challenges concerning both a more formal structure and, not least, the user participants becoming more proactive – which means taking more initiative to raise issues themselves and representing user voices that are constructive but critical towards the institutions and organizations. This leads us to the question of what factors may create fruitful conditions for the user participants to be more proactive.

**What are the prerequisites for making user councils function better?**

There are several prerequisites for making user councils more valuable for both the agencies they belong to and for the user participants and their organizations. I have categorized the prerequisites into the following factors to consider: the framework conditions including the attitudes of the agency representatives; factors concerning the user participants; the responsibilities of the user organizations, including challenges of recruiting user participants; and development of a more holistic system of user involvement with the user council as one of several means to that end. These recommendations are based on analysing the data from interviews.

**The framework conditions and the attitudes of the agency representatives**

Generally, awareness of the existence of user councils, their membership, responsibilities and activities needs to be raised amongst decision-makers in agencies, employees, service users and other relevant stakeholders. This is a basic precondition for relevant stakeholders to consider and use the councils as a means of user influence.

The work of the councils also has to be formalized. As mentioned earlier, in many of the user councils in my sample there is a good practise of formalization, but in some of them there is a need for improvement concerning procedures for appointing the members, deciding the election period, deciding on a mandate for the council and so on.

One prime possibility for improvement, especially concerning councils for disabled people in the municipalities, is the implementation, as a standard procedure, of a position for the councils in the hearing process for such things as cases, issues and plans. The user participants in the councils have indicated that this is not currently a routine practice, and that it depends greatly on the manager of each case remembering to involve the user council in the process. In addition, the cases must come to the council early enough in the process to allow for the possibility of user council’s suggestions being taken into consideration.

Agency representatives have to take the user council seriously and invest time and resources in the work and organize the activities in a way that promotes a vital and well-functioning user council. This also requires the agency representatives to be explicit in their expectations of proactive and constructive and critical user voices in the user councils.
The user participants

There are several potential reasons why the user participants are less active and critical than they would like, or the agency informants would like them, to be.

Some of the user participants seem unsure about what they actually can do and what kinds of issues they can work for in the council. Probably, this is partly because of lack of experience, but also partly because of lack of relevant education and training (see next factor).

Individual levels of ambition and ability to participate are also variable among the user participants. Some of them are involved in so many user councils that they probably do not have the time to be more active in any of them. The possibility of ‘consultation overload’ is a relevant topic for discussion in this context (Barnes 1999), especially in relation to how some of the user participants are involved in several user councils in different agencies and welfare areas. Most of the user participants have disability pension, but some of the participants are employed. Consequently, they have limited time to participate because the meetings and other activities concerning the user council commonly occur during the day and can conflict with work schedules.

Another interesting question is whether selecting a user participant as the leader of the user council can make the council as a whole, as well as the members individually, more active. Findings from the interviews indicate that the effect depends on how the leader fulfils the role. It might be the case that, depending on his or her personality, such a leader might dominate the proceedings and thereby reduce the initiative and engagement of the other members of the council. If the council has an overbearing leader, combined with other members that are not inclined to be particularly active, the total activity of the council might be reduced. But if the leader can activate the potential of the other members, for instance by dividing responsibilities between them, then selecting a user participant as leader is probably a smart way of increasing the activity, and thereby the importance, of the user council. The findings from the studied sample indicate that the user participants are more active in promoting cases in the councils that have a user participant as leader.

The responsibility and challenges facing user organizations

The user organizations have the responsibility of educating and training user participants. This is of crucial importance for user participants as it increases their knowledge and skills and thereby improves their self-confidence and makes them feel more secure in their role in the user councils. The literature of user involvement also stresses the importance of learning and training (Beresford 2012). Barnes (1999, 82) underlines that developing a proactive approach demands a ‘capacity-building amongst communities of people whose identities have been devalued and who, individually, have been largely powerless to achieve change’.

This education and training needs to encompass a basic education in user representation as well as more advanced training in topics related to activities of the councils. In addition, it must include arenas for exchange of experiences, through which less experienced representatives can learn from those with more.

It is also of crucial importance that the user representatives are able to get input from the members of the organizations they represent, and that they can raise issues of importance in the user councils. The organizations face a challenge concerning recruitment of user participants to the user councils, especially younger people. There are many participants that are members of several councils, and the average age of the participants is high. As the demand for user participants increases, it will be very challenging to recruit a sufficient number of competent qualified individuals.

A more general system of user involvement and the user council as one of several means

User councils’ real significance to and influence on the welfare areas they cover and/or the agencies they are connected to, must be considered in a broader context of user involvement, including, for
instance, satisfaction surveys, hearing processes, information to users so they are able to participate, etc. It is important to consider the general context of user involvement and what kind of means must be used to obtain what purposes, and the connection between them. In this way the welfare agencies may develop a more comprehensive and continuously system of user involvement where the different means complement one another.

The user councils could be engaged in the development and evaluation of satisfaction surveys, and also be concerned with how user participation on the individual level is implemented and functions. Satisfaction surveys may be seen as a part of a consumer-focused approach where the users express their views on different aspects of the service delivery in a passive and reactive way (Wistow and Barnes 1993). This is an expression of the instrumental approach to user participation. The user councils may have a role as interpreters of this information, and give advice to the agency on how to act based on the results. In this way the user councils go beyond the consumer approach of consultation to be advisory organs for the agencies. As a result, the user participants can fulfil their role as democratic representatives.

Conclusion

As mentioned in the introduction, some researchers in the user involvement field do not find any particular hope for influence by user representation in service systems, and argue that the organizations for disabled people should therefore concentrate their efforts on activities based on their own initiatives (e.g. Beresford and Campbell 1994). I will question that as a general conclusion by asking if the welfare state context may be important to consider. The Nordic welfare states are characterized by trust, consensus orientation, long traditions of user participation and a collaborative relationship between the state and the civil society (Alm Andreassen 2006). Perhaps, then, the potential for user councils that are better functioning and more influential is greater in the Nordic welfare states than in more liberal welfare states which are characterized by mistrust and conflicts. This kind of user participation is a reality, and will probably increase in the future. In my opinion this is an arena that should be used, and I have argued in favour of the possibilities for making improvements in the way the user councils are functioning. There may be potential for developing a more proactive attitude among user participants in the councils. I am in accordance with Barnes (1999, 87) that: ‘Inclusion within processes of governance is significant because of the recognition of competence, and the legitimacy of the presence of people previously regarded as incompetent to participate within decision-making processes’.

The importance of user councils must be evaluated in a broader context as one of several different means of user participation. This will probably contribute to an increased commitment and involvement from users in different ways in order to improve the services offered by the agencies. The user councils can be organs for discussing, evaluating and advising on the different types of user involvement in a welfare agency or sector. By thinking about and planning the different means of user involvement in a holistic perspective, it is possible to combine and intertwine the democratic and instrumental approaches to user involvement.

However, although the user councils’ may become more active and the user participants more proactive, we do not know what impact this will have for the agencies the user councils are connected to. What impact the user councils may have towards different aspects of the agencies’ activities is an important question for further empirical research. Beresford (2012, 34) also claims that over the last few years ‘much greater emphasis has been placed on demonstrating the “impact” of involvement, that is to say, evidencing what effects it actually has’. Carr (2012, 49) also refers to ‘the next wave of evidence on how service user participation could result in change that makes a real difference to people’s lives’. This is probably important for mobilizing users to participate. Martin and Boaz (2000, 51) claim that some groups’ unwillingness to become involved stems in part ‘from the belief that it will not result in tangible improvements in services or in their quality of life’. If the effects of the user participation in the councils prove to be very low and of minor importance, then the organizations of disabled people may consider if they should use their resources on other more influential activities.
Disclosure statement

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