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ARTICLE

# The Participation of People in Vulnerable Situations in Interest Organisations: A Qualitative Study of Representatives Views

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**Abstract**

People in vulnerable situations have the same right as others to participate in public spheres and influence health and welfare services. However, organisations that support these people and promote their interests are essential to their participation. This study investigated how people in vulnerable situations with lived experiences of using public services participate in organisations representing their interests. Fourteen representatives from eight interest organisations were interviewed. The first theme we developed – namely, *participation as representatives of the organisations*, revealed that a spokesperson's role is connected to competence and that users of public services rarely obtain such a position. However, people with experience of using public services participate as living examples in external activities, increasing the groups' visibility through their physical presence and their stories. The second theme was titled *participation in organisational activities.* The extent to which people with lived experiences participate in formal meetings varies, but they are often consulted by the organisations and attend events and informal gatherings. Notably, people in vulnerable situations interact with and, thus, influence the service-providing organisations. This article discusses the findings in light of representation theory and their implications for practice.

**Keywords:** interest organisation; interest group; user participation; representation; people in vulnerable situations

## Introduction

The aim of this study was to explore how people in vulnerable situations with lived experiences of using public services participate in organisations that represent their interests. People in vulnerable situations are described as people who experience inequality, discrimination, and a lack of fundamental human rights (Peroni &

Timmer, 2013). In this paper, we focus on people with intellectual disabilities, people with dementia, asylum seekers, people with substance use problems, and children in contact with child welfare services and add to the ongoing discussion about how these people can obtain a stronger voice in welfare development (Gathen *et al.*, 2022; Ishkanian, 2022).

Since the participation of all citizens in society is a fundamental value and goal of modern democracies, the issue of user participation also deals with the democracy of a welfare state (Beresford & Carr, 2012; Vedung & Dahlberg, 2013). User participation at service, system, and political levels is a way of democratising the welfare state and improving welfare services by making them more responsive to their users' needs (Dent & Pahor, 2015; Fotaki, 2011). Official papers state that those affected by public services are entitled to be involved in the development, planning, implementation, and evaluation of these services (White Paper 34, 2015–2016). Power in the context of user participation has often been understood as the ability to make or influence decisions. Arnstein's (1969) ladder illustrates how power among users can range from non-participation to varying degrees of tokenism and citizen power. According to Arnstein (1969), tokenism, through the levels of information, consultation and placation, provides possibilities for being heard without guarantees for wielding influence. Thus, participation might become perfunctory or symbolic. In Arnstein's (1969) view, only partnerships, delegated power, and citizen control are indicators of user participation, since these are the levels at which users influence decision-making processes. Arnstein's ladder has received much criticism over the years as scholars have deemed it normative and believe it fails to capture user participation's complexity and dynamic nature (Tritter & McCallum, 2006). Nevertheless, the model still provides a useful framework for addressing the issue of tokenism. To avoid tokenism, scholars have suggested working to empower service users, developing new models of participation, and increasing the focus on impact and evaluation related to user participation (Ocloo & Matthews, 2016).

User participation is a charged concept with varying ideological underpinnings (Askheim *et al.*, 2017). From a consumerist viewpoint, it aligns with new public management strategies in its emphasis of user choice and satisfaction (Wistow & Barnes, 1993). In contrast, democratic ideologies consider the intrinsic value of user participation and emphasise it as a right, as its participatory and deliberative dimensions can help deepen representative democracy (Vedung & Dahlberg, 2013). Notably, representative democracy has proved insufficient for promoting the voices of all people; therefore, the participatory dimension is given greater prominence in order to increase people's proximity to decision-making and include them in debates about matters that concern them (Dahl, 2020). In addition, the deliberative dimension emphasises that all people have the right to be included in public debates where they can thoughtfully examine all relevant arguments and, thus, improve the quality and legitimacy of subsequent decisions (Habermas, 1984). According to Habermas (1984), deliberation should also focus on decreasing power asymmetries and increasing competence among weaker groups, which is often achieved through representative assistance.

In a European context, an increasing number of organisations are involved in user participation activities. These organisations are heterogenetic in their structures, members, ideologies, and goals and are often involved in service provision and advocacy work (Beaton *et al.*, 2021; Markström & Karlsson, 2013; Smith *et al.*, 2016). Furthermore, they rely on internal and external legitimacy, which must be continuously developed, maintained, and repaired (Gnes & Vermeulen, 2018). Strategies to develop and maintain legitimacy include establishing democratic structures, involving people with relevant lived experiences in the organisations, and ensuring that representatives know the groups they represent. The Norwegian Welfare State provides extensive services, and civil society organisations are more concerned with advocacy work than service provision. However, the organisations vary, and service provision is also essential for some of them. Official documents also recognise these organisations as significant contributors to the development of welfare services (Norwegian Official Report 2018: 6, 2018), and public services have started employing former service users as experts by experience or as peer workers, particularly within the mental health and substance use field. In line with the development of civil society in general (Meyer & Bromley, 2013), interest organisations are increasingly formalised. Moreover, the members of such organisations often consist of a combination of service users, next of kin, and professionals without personal experience. Moreover, the organisations vary in size and economic resources, but most have some employed staff in addition to volunteers.

The international research literature describes how interest organisations have become professionalised and knowledge intensive due to the employment of professional staff (Meyer & Bromley, 2013). As a result, scholars suggest that these organisations may face conflicts between civil society logic and professional logic (Eriksson, 2015; Schoenefeld, 2021; Waardenburg, 2021) and that closer links to the government can cause changes in their ideologies, structures, and activities (Van de Bovenkamp & Trappenburg, 2011). Furthermore, these issues can also lead to interest organisations losing contact with their traditional member bases (Brandsen *et al.*, 2014) or even struggling to represent the heterogeneity among their members while creating a unified voice of influence (Pijl & Sminia, 2004).

Today, representatives of interest organisations tend to be more professional, and they are expected to develop relevant competencies and expert knowledge that go beyond mere familiarity with the situation and the perspective of the groups they represent (Frank *et al.*, 2012; Krick, 2021; Learmonth *et al.*, 2009; Martin, 2008b). Consequently, representatives have to find a balance between voluntary and professional logic (Andreassen, 2018), presenting authentic experiential knowledge to maintain their critical role while ensuring a collaborative relationship with the welfare services (Jones *et al.*, 2021). Thus, people in interest organisations may be perceived as unrepresentative, atypical, or inauthentic because of their methods of engagement (Barnes, 1999; Beresford & Campbell, 1994; Martin, 2008a), and professionals in health and welfare services might question whether such individuals have a collective or individual perspective (Mossberg, 2020). Furthermore, people with lived experiences of using public services may perceive the representatives as, therefore, not speaking on their behalf and not viewing them as real users (Bartoszko, 2021).

The individual stories of these people may also be given precedence over collective knowledge due to increasingly individualised political agendas (Näslund, 2022). Andreassen *et al.* (2014) used the term *professional amateurs* to describe the role of representatives of voluntary and social movement organisations and how their self-governed, educative work leads to professionalisation. The authors argued that the role of a representative must still rely on lived experiences of using public services. We see an ongoing debate regarding who can be considered representatives and how they should act on behalf of people in vulnerable situations. In this study, we use Pitkin's (1967) conceptualisation of representation to explore how people in vulnerable situations can participate in organisations and how they are represented – issues which also deal with the legitimacy of organisations and representatives. Pitkin (1967) describes four typologies of representation: formalistic, symbolic, substantive, and descriptive. Formalistic representation gives importance to accountability and authorisation, which means that a representative should be responsive to the group's interests, transparent in decision-making, and elected according to legitimate criteria. Symbolic representation, as the term suggests, means that a representative's role is symbolic – it is a role they have as long as the people they represent view them as representatives. Substantive representation focuses on the representative's activity as the central element, which must align with the preferences of the group being represented. Finally, descriptive representation means that the representative resembles the represented in terms of physical attributes, interests, or life experiences. For people in vulnerable situations, descriptive representation has been highlighted as increasing the likelihood of their interests being taken care of, promoting the group's visibility, and resulting in a more thorough consideration of other stakeholders' arguments (Dovi, 2018; Haider-Markel, 2007; Mansbridge, 1999).

According to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006), all people have the right to participate fully in political and public life either directly or through chosen representatives. Despite this, people in vulnerable situations are still underrepresented in user participation processes due to health problems, disabilities, and structural and social barriers, making interest organisations pivotal in terms of promoting their interests (Brandsen, 2021; Matthies, 2016; United Nations, 2006). These groups may also lack personal resources or experience other barriers to participation (Frank *et al.*, 2012; Raz *et al.*, 2018; Weetch *et al.*, 2021), often requiring assistance, either completely on their behalf or through collaboration, to promote their interests. Since organisations are often *for* but not *of* people in vulnerable situations (Schicktanz *et al.*, 2018), further knowledge about how such people participate in organisations is needed to identify ways of promoting their voices. Accordingly, this study aimed to explore how people in vulnerable situations in Norway participate in organisations by addressing the following research questions:

1. How do people in vulnerable situations participate in interest organisations?
2. What are the dilemmas related to the representation of people in vulnerable situations?

## Methods

### Study Setting and Design

This study is part of the research project Challenges of Participation. The overarching project investigates user participation among five groups of people in vulnerable situations in Norway: people with intellectual disabilities, people with dementia, asylum seekers, people with substance use problems, and children in contact with child welfare services. Accordingly, the role of the present study was to gain insights into these groups' user participation. As this topic has received little research attention, a qualitative design with explorative and descriptive elements was deemed appropriate for the study.

## Recruitment and Informants

People in interest organisations have extensive knowledge and experience regarding the research topic and were deemed able to provide information-rich data. A combination of strategic and snowball sampling was used to select the informants. The first author conducted online searches for relevant organisations and consulted academics with expert knowledge of the field to recruit relevant informants. Then, the first author contacted the organisations via e-mail, using either their general e-mail addresses or those of persons who were listed as contacts on their websites. After corresponding with the contact persons, these gatekeepers helped recruit informants and suggested other organisations to contact. The eight organisations chose which representatives would be interviewed and helped arrange the meetings. At first the representatives central to each organisation were interviewed, and they were asked to suggest other potential informants. During this process, we emphasised that we wanted to interview people with different backgrounds and roles, including people who had lived experiences of using public services.

The final sample consisted of 10 women and 4 men between the ages of 20 and 75. The sample consisted of eight employees and six volunteers at the central and/or local levels of eight organisations representing the following groups: people with dementia (three informants), individuals with substance use problems (two informants), asylum seekers (two informants), people with intellectual disabilities (three informants), children in contact with child welfare services (two informants), and children of parents with substance use problems (two informants). Three informants had personal experiences of using public services, two had experiences as next of kin, seven had relevant professional backgrounds, and two had next of kin with professional backgrounds. Their professional backgrounds were associated with health, sociology, and law. The participant recruitment concluded when the materials collected were deemed to have enough information power to address the research questions (cf. Malterud *et al.*, 2016).

## Data Collection

The first author conducted 13 semi-structured interviews in Norway between August 2019 and October 2020 at places chosen by the informants, which were most frequently at their organisations' offices. Twelve informants were interviewed individually. In one interview, two informants from one organisation were interviewed together at the organisation's request. In total, eleven interviews were conducted in person. Due to the subsequent advent of the COVID-19 pandemic, the last two individual interviews were conducted via telephone. Before the interviews, the informants gave written or oral consent to participate. The guide for the semi-structured interviews consisted of questions about the informant's organisation and role, the informant's experience of user participation and its associated impact, how to observe and evaluate the results of the organisation's work and user participation, and how the voice of the user group had been promoted. The interviewer encouraged the informants to talk about their experiences and anything they considered important regarding the research focus. How people with lived experiences participated in the organisations was not a main topic in the original interview guide. However, the first informant raised the issue at the start of the first interview, and subsequently, it became a point of interest in the other interviews as well. The interviews lasted 65–100 minutes each and were audio recorded. The first author transcribed the interviews verbatim, and then the text was restructured slightly (i.e. to delete repetitive speech, improve grammar, and change relations/names) to ease the reading of the same and ensure anonymity, without altering the meaning of the content.

### Data Analysis

Braun and Clarke's (2006, 2019) framework for thematic analysis was chosen to analyse the data material. This approach to thematic analysis opens up for adjusting and changing theoretical perspectives and allows the researchers to be creative. We deemed the approach appropriate since the interviews were explorative and dealt with various service user groups, organisations, and contexts. The three authors, led by the first author, were involved in the analysis. An abductive approach was followed for the analysis, with both data and theory affecting the interpretations.

Starting with a focus on user participation and its associated impacts, the theory of user participation was the initial analytical perspective. After conducting the first complete coding, we developed a large number of codes with a broad focus. Most of these codes were superficial, describing activities in the organisations, external activities and representation, political views, views on public actors, and the results of the organisation's work and advocacy. These codes were both particular and broad. During the coding process, we developed an interest in the organisational role of people in vulnerable situations, and 11 of the 14 informants did not have lived experiences of using public services. The informants themselves brought up this issue in the interviews. Therefore, we decided to revise the research questions and conduct a detailed analysis of how people in vulnerable situations participate in the organisations. This resulted in a more specific coding guided by the revised research questions. Here, we also introduced new theoretical perspectives, notably representation and professionalisation. These perspectives were introduced after adjusting the research questions. We have been particularly inspired by Pitkin's (1967) conceptualisation of representation and research problematising the distinction between organisations *for* and *of* people with service user experience (Schicktanz *et al.*, 2018). These perspectives helped us develop a more meaningful understanding of the data. The following coding focused on characteristics of the formal representatives, how and in which activities people with experience participated (e.g. elections, meetings, external representation, gatherings), the organisation's services and the role of next of kin. Based on this, we developed themes connected to participation in the organisations' formal and informal parts and to representation. The analysis was an iterative process, and we adjusted and refined the themes until finalising the paper, resulting in the themes presented in the result section.

### *Ethics*

This study was recommended by the Norwegian Centre for Research Data (reference number 505481). Before the interviews were held, the informants received information about the study and were assured of their anonymity in the study reports. They were also given the opportunity to withdraw from the study. The competency to provide consent was not an issue for any of the informants.

## Results

Two main themes were developed from the analysis: *participation as representatives of the organisations* and *participation in organisational activities.* The first theme relates to representation and describes the most direct way of participating in an organisation. The second theme describes both indirect and direct ways of participating in activities that affect an organisation.

### *Participation as Representatives of the Organisations*

The informants stated that people in vulnerable situations could be and have been representatives of interest organisations. However, many expressed that it was challenging for people using or affected by public services to be spokespersons and that they most often participated in meetings as living examples.

#### *Participation as Spokespersons*

The scope of being a spokesperson for an organisation can range from being a full-time job to an unpaid task. The informants stated that being a spokesperson required knowledge about the group being represented, the welfare system, and user participation. In addition, the informants, as spokespersons at higher levels in their respective organisations, stressed the importance of having up-to-date knowledge of political processes, public debates, and research. Several informants declared that many tasks were highly specialised, and they often referred to other people in the organisations as more competent than themselves. The informants emphasised that formal competences, such as a degree in health, law, or another relevant field, were crucial for employees in these organisations. One informant explained this as follows:

> We also have people who work as volunteers, but most of our caseworkers are employees. Because having that job requires a lot of knowledge, you basically have to be a lawyer and get acquainted quite quickly with the regulations of and information about the country.
>
> Heidi, organisation for asylum seekers

Furthermore, the informants conveyed that the situation was more nuanced in the case of unpaid spokespersons. People with current and previous lived experiences of substance use served as representatives of the organisations, and most of them were in stable life situations with controlled substance use. In addition, most of the representatives of the organisations for children of parents with substance use problems and organisations for children in contact with child welfare services were adults with similar lived experiences. The informants believed that few children were recruited because of their complicated life situations. Notably, many did not participate in interest organisations until their use of such services was behind them. In contrast, few spokespersons in organisations for people with intellectual disabilities, people with dementia, and asylum seekers were people with lived experiences. For all the groups, the informants highlighted the professional language and culture in user participation channels, such as councils and committees, as a barrier to becoming spokespersons. The informants also emphasised that one needs special competences, oral and written presentation skills, rhetorical skills, relational skills, and patience to be an active participant. Informants with and without professional backgrounds stated that courage and self-confidence were essential requirements for being active in meetings with public actors, particularly if they were unfamiliar with the terminology being used. Furthermore, many informants conveyed that the organisations had become more strategic in ensuring that their spokespersons were qualified; they spent more time and resources educating and preparing their representatives for meetings with public actors. One informant explained the scenario as follows:

> I think they have become stricter with who can represent the organisation. The follow-up before and after is much more systematic. I have noticed this because I have been on a user council. The follow-up I have received has been much more systematic and demanded much more from me than before.
>
> Lone, organisation for children with substance-using parents

The informants emphasised that people with lived experiences of using public services should be spokespersons of relevant interest organisations. However, obtaining the necessary qualifications and language skills may be difficult for people with illnesses, disabilities, or strenuous life situations. The informants provided examples of people with dementia and intellectual disabilities who had previously experienced such obstacles, emphasising that the representation of these groups depended heavily on facilitation and support. Notably, one informant highlighted that persons with moderate intellectual disabilities led a local branch of the organisation, although these individuals often required facilitation and support. Many also stated that a lack of time and resources was critical in terms of preventing people in vulnerable situations from becoming representatives of organisations.

### *Participation as Living Examples*

The informants stated that people in vulnerable situations were often involved in external activities as living examples; the activities involved lectures, meetings with public actors, media cases, and external councils/committees, amongst others. According to the informants, the physical presence and individual stories of these people could increase the groups' visibility, transfer knowledge to public actors and society, reduce stigma, and influence concrete cases. For example, one informant described a meeting with politicians as follows:

> We provided people with lived experiences; someone with dementia was present at all meetings and talked about what it was like to live with dementia. The minister said that this was one of the finest meetings he had attended.
>
> Hanne, organisation for people with dementia

However, many informants expressed their scepticism about the way personal stories were shared at seminars and conferences. They emphasised that knowledge dissemination is the most crucial requirement for informing and changing practice and that individual stories should be used carefully to form a framework of understanding, as they may contribute to cementing people's established perceptions of the group.

> They invite someone who has a sad story to underline what someone in the room thinks and wants. It works a bit like a cultural element. … It is usually a person with a lived experience unfolding their entire emotional register from twenty minutes to an hour. However, what it really is … it is a short break from research methods and statistics so that the ladies who sit with their knitting can cry a little and feel what they do is valuable.
>
> Fredrik, organisation for children with substance-using parents

While appealing to emotions is necessary, as the informants stated, presentations of individual stories should not turn the audience into "emotional hostages", as Fredrik later put it. In addition, the informants expressed that presenting one's own story could be emotionally challenging. Finally, the informants expressed different views regarding the impact of presenting individual stories: some believed that the audience was only emotionally impacted at that particular time and place, while others believed it had a more significant effect.

> Of course, it has the biggest effect on people when you have your own experiences in terms of communication. It is like journalism; you have to have a case, and you must have someone you refer to. Politicians and those administratively responsible are no different from other people. They get affected.
>
> Tiril, organisation for people with intellectual disabilities

The informants stated that a generalised and professional presentation of the group's experiences was preferable and that anecdotes could work well as additional "spice", as one informant put it.

## *Participation in Organisational Activities*

The informants said that people in vulnerable situations participated in formal and informal meetings, events (such as summer camps and seminars), gatherings, and consultations. In addition, they mentioned that the participation of next of kin promoted the voices of these people within the organisations.

### Participation in Meetings, Events, and Gatherings

The informants stated that all members of the organisations could participate in formal meetings (e.g. elections, general assemblies). The informants who represented people with substance use problems stated that the people with similar lived experiences who took part in formal meetings were in stable life situations with controlled substance use. The informants representing organisations for children in contact with child welfare services and children of parents with substance use problems said that those who participated in formal meetings were primarily adult volunteers or employees. In contrast, informants representing asylum seekers said that only a few people with lived experiences were members of the organisation and, consequently, participated in formal meetings. Participation in formal meetings could be difficult for people with dementia and intellectual disabilities due to a lack of resources and time.

> Researcher: I noticed that the organisation wanted to include people with intellectual disabilities in councils and committees. Did you all manage to do that?
>
> Dina: No. That is really bad. I think it is a shame, and it is about what we were talking about earlier – time. It requires resources.
>
> Dina, organisation for people with intellectual disabilities

Despite the various obstacles, people with intellectual disabilities and dementia had participated in some formal meetings when provided with support, and one informant stated that a council consisting of people with mild to moderate dementia functioned as an advisory body in the organisation. The informant further stated that the council was resource intensive because of costs associated with travel and support and emphasised the need to adjust the information it gave to people with dementia. Nevertheless, she expressed that the council had made a significant impact on the organisation's view of how people with dementia can participate.

The informants claimed the importance of consulting experienced people at events and gatherings, such as summer camps or lectures, in the form of social networking. They found such events to be more accessible than formal meetings for people using public services.

> We have many gatherings and camps and other such activities for members. Often young people come to the summer camps, and they are still in child welfare services.
>
> Maria, organisation for children in contact with child welfare services

Many informants considered informal gatherings and events essential for staying in touch with people at the grassroots, as they allowed representatives to speak to people about issues that concerned them. In addition, some informants said that they received valuable inputs through the organisations' digital platforms and via direct requests from people in vulnerable situations.

### Service Reception and Participation by Proxy

Many informants spoke of their organisations' service provisions as essential for staying in contact with the groups they represented. For example, one participant said the following about handing out damage-reducing drug user equipment:

> We distribute user equipment at the street level. It is an excellent approach to getting in touch with the substance use milieu. You come with something they need to take their drugs safely. So, you are somehow not excluded. It is a good way to start a conversation, and we are very dependent on knowing where the shoes pinch those who wear them.
>
> Nina, organisation for people with substance use problems

Many organisations provided different services to the groups, such as legal assistance, chat services, and information. The informants reported that such services made it possible for them to interact and develop knowledge about the current issues faced by people in vulnerable situations. This affected the representatives' work by directing their focus and standpoints in concrete cases. Moreover, the informants expressed that extensive contact with people in vulnerable situations had contributed to their unique knowledge about the groups' experiences, needs, and perspectives.

Several informants underlined the importance of next of kin in promoting the voices of people in vulnerable situations, either on those people's behalf or together with them. For example, the next of kin of asylum seekers could help the latter get in touch with a relevant organisation and even translate their interactions with the organisation when needed. Notably, the informants talked about an increased focus on the participation of people with lived experiences in organisations for people with dementia or intellectual disabilities. Nevertheless, next of kin were still essential for promoting their voices. For example, one informant talked about a meeting in a nursing home and later about the organisation as follows:

> Yes, everybody can come. I do not know of anyone with dementia who has been there. It may be that I do not know them well enough. However, my impression is that mainly quite resourceful relatives come. … The association was for relatives, actually relatives and all residents. But it was run by relatives. Everyone on the board was a relative.
>
> Einar, organisation for people with dementia

The informants said that the next of kin of people who lacked communication skills often functioned as interpreters. However, next of kin promoting their own perspectives on their family members' behalf or not noticing changes in preferences were mentioned as possible pitfalls. Nevertheless, the informants regarded the next of kin of persons with dementia or intellectual disabilities as essential resources because of their in-depth knowledge of the affected person's life and background.

## Discussion

This section discusses the findings related to how people in vulnerable situations participate in the organisations representing them before focusing on the dilemmas of representation. The findings align with studies that have described spokespersons of interest organisations as people with experience in using public services, next of kin, or people with professional backgrounds (Frank *et al.*, 2012; Raz *et al.*, 2018; Schicktanz *et al.*, 2018; Weetch *et al.*, 2021). However, the findings from this study also suggest that participation as a living example is more common than participation as a spokesperson among people who currently use public services. The informants connected this trend to the competence requirement in terms of being a spokesperson, which is in line with research suggesting that organisations and representatives are becoming more professionalised and focused on building such competence (Andreassen *et al.*, 2014; Krick, 2021; Learmonth *et al.*, 2009; Martin, 2008a). This development could also lead to an organisation pursuing professional logic at the cost of civil society logic. The groups included in this study also seem less involved than many other service user groups in the formal organisations, which may have to do with, for example, disability, language skills, formal citizenship, and health problems. Combined with structural and societal marginalisation, these factors may create barriers to taking part in the formal aspects of the organisations and also create difficulties with regard to influencing user participation processes (Komporozos-Athanasiou *et al.*, 2018). Despite their inclination towards involving these groups in the respective organisations' activities, many informants reported these barriers to participation and highlighted the need for resources within the organisations. These barriers may make it difficult for people in vulnerable situations to choose their representatives (United Nations, 2006), as participation in the formal procedures for selecting their representatives in the organisations may be difficult. It is paradoxical that such organisations tend to highlight the democratic right of people in vulnerable situations to influence public services when these people find it challenging to get involved in the formal aspects of the organisations. This gives rise to the question of how public services and authorities should facilitate participation when the associated organisations face difficulties in doing so themselves.

The results suggest that people in vulnerable life situations play a larger role in the informal than in the formal organisation. Little involvement as formal spokespersons and in decision-making processes may indicate participation that can result in what has been described as tokenism (Arnstein, 1969; Ocloo & Matthews, 2016). However, it may also be that people in vulnerable situations have limited personal resources and find it challenging to develop the competence required to participate as representatives and in formal processes. Changes in life situations might also result in people becoming more vulnerable (e.g. people with dementia and declining health), which illustrates how it could be hard for those currently using public services to participate in the associated organisations. In contrast, some people might develop this competence or enter more autonomous life situations, which could make it easier to participate in the organisations. Nevertheless, these people are then often past and not current service users. In this regard, there are dilemmas concerning to what extent one can expect people in vulnerable situations to participate in the formal aspects of an organisation, since it may have negative consequences for the individuals and for the efficiency of the organisation. As the findings show, negative consequences for the individual involved can be a particular challenge when telling one's story, indicating that the organisations must pay attention to this issue. Moreover, the impact of sharing individual stories seems unclear since the informants had different views regarding the outcomes of these presentations. Withstanding the rhetorical effect, taking care of individuals should be a priority for the organisations. In doing so, some informants stressed the importance of preparation, having consciousness about one's own situation, and a clear link between individual's story and the overarching message. As such, we believe individual stories have a place in an organisation's work but that they must be used carefully and with a clear purpose.

The study sample was small, but during the research process we developed some thoughts about the similarities and differences between the groups. We believe this may be due to some of the specific vulnerabilities of the groups and the fact that their different characteristics could lead to different challenges and opportunities regarding representation. There seem to be differences regarding cognitive capacity and language, since verbal competence plays a crucial role in the ability to become a formal representative. These features are most present for people with dementia and intellectual disabilities and asylum seekers, which could explain why these groups rarely seem to fulfil the role of formal representatives. Using Pitkin's (1967) typology, these groups seem to rely on substantive representation. Within the other organisations, the representatives seem to be more in line with what has been labelled descriptive representation and the concept of professional amateurs (Andreassen *et al.*, 2014). Nevertheless, it is interesting that even among these groups there are few current service users who are formal representatives. Moreover, for many, representation has become a full-time job, and this brings the question of to what extent they are representative of the service user group. Perhaps we need to develop a new understanding of how service users are represented, since the existing theories do not take into consideration the reality of people in vulnerable situations.

Another interesting finding was that many spokespersons, particularly for those with dementia and intellectual disabilities, tend to be next of kin. In some understandings of user participation, next of kin are included in the concept of service users (The Patient and User Rights Act, 1999). As such, they could, to some degree, be understood in terms of Pitkin's (1967) concept of descriptive representation because they have interests and experiences that resemble those of people in vulnerable situations. In many circumstances, proxy representation could be the most appropriate way of seeking influence. Since proxy representation relies on viewing a group as unable to present its interests directly, it is based on the interpretation of the facilitators. If organisations do not maintain close contact with the groups they represent, they may find it challenging to identify these people's interests. As research has shown that user participation can have an impact on the stakeholders and organisations involved (Gathen *et al.*, 2022), engaging the service users more directly can facilitate empowerment and help avoid tokenism while contributing to service development (Ocloo & Matthews, 2016; Vedung & Dahlberg, 2013).

How people in vulnerable life situations are represented might also be affected by the general professionalisation of this organisational field. The findings suggest that user participation is becoming increasingly demanding due to highly specialised and complex services, and thus, organisations and representatives may feel pressured to increase competence levels and become more professionalised. However, professionalisation and the lack of representatives with lived experiences could lead to interest organisations being considered inauthentic and unrepresentative of vulnerable groups by both members and public actors (Barnes, 1999; Beresford & Campbell, 1994; Martin, 2008a), decreasing the organisations' and representatives' legitimacy. Nevertheless, professionalisation may be an effective way of obtaining results and meeting an organisation's goals, which may in turn address the most essential issues of the group and benefit internal and external legitimacy. Professionalisation may also lead to increased legitimacy, since public actors tend to be more responsive to and may acknowledge organisations and representatives using professional argumentation and language. This could, in turn, create a dilemma of whether top-down or bottom-up management is suitable for the organisations, which could increase external legitimacy at the cost of perceived legitimacy among the groups represented. In addition, professionalisation may result in organisations and representatives applying professional logic at the expense of civil society logic and, consequently, toning down or abandoning their critical roles.

### *Limitations*

This study explored representative perceptions of how people in vulnerable situations participate in interest organisations; thus, it did not focus on the specific practices of individuals participating in the organisations. Furthermore, the study included a small number of informants from each group and relatively few organisations. Given the heterogeneity among the organisations in this field, representatives from other organisations could have provided different information on the organisational participation of people in vulnerable situations. In addition, many other groups other than those included in this study are in vulnerable situations. Nevertheless, we believe that the data have high information power since the informants had significant knowledge and experience related to the research topic, and the study was theoretically informed. Regarding the transferability of the findings, the democratic system and extensive welfare state of the Norwegian context should be considered. However, the findings of this study may be relevant in other countries that emphasise the strengthening of the voices of people in vulnerable situations.

## Conclusion

A significant finding of this study is that it can be difficult for people in vulnerable situations, particularly those currently using public services, to be representatives of interest organisations. Another significant finding is that due to their past experiences, people in vulnerable situations function as living examples in external activities and participate in many organisational activities. However, many of these people require assistance to participate. Thus, there seems to be an emphasis on the substantive representation of people in vulnerable situations, while descriptive representation plays an increasingly vital role in increasing the visibility of and sympathy towards these groups in organisations' user participation and advocacy activities. The findings can provide such organisations and their representatives with helpful, relevant knowledge about how to promote their members' voices and promote the development of new models to help people with experience of public services to participate in the organisations. Moreover, the findings can facilitate a more critical perspective on the role of organisations and representatives, which may, in turn, increase their legitimacy and influence.

This study contributes new and unique knowledge to the literature on user participation, focusing on how people in vulnerable situations can participate in interest organisations. As this topic was explored through representative perceptions, future research could examine the actual practices implemented. This knowledge is essential for developing new models to increase participation and direct representation. In addition, future research should explore how user participation in a welfare state can be modified or changed to allow for more direct participation of people in vulnerable situations.

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