

Service user participation in decision-making – a qualitative study from a services user’s perspective

Maria Bendtsen Kronkvist, Patrik Dahlqvist Jönsson, Karl-Anton Forsberg and Mikael Sandlund

Abstract

Purpose – *The purpose of this study is to describe participation in decision-making among service users with severe mental illness.*

Design/methodology/approach – *Service users want to participate in decision-making and in the planning of their care. There are widely known methods, such as shared decision-making, that could be used to facilitate service user participation. Three focus group interviews were conducted with the participation of 14 persons with mental illness and/or substance abuse who were service users at two Swedish Homes for Care and Residence (HVB). Data were analyzed by qualitative content analysis.*

Findings – *Two themes emerged: service users’ involvement in decisions is hampered by the professionals’ approach and adequate information and experience of participation means greater empowerment.*

Research limitations/implications – *Although it is known that service users would like to have more influence, and that methods like shared decision-making are recommended to empower service users and improve the decision process, research on these matters is limited.*

Practical implications – *This study reveals that there is a need of more systematic decisional support, such as shared decision-making, so that service users can be seen as important persons not only in guidelines and policy documents but also in clinical practice.*

Social implications – *The findings indicate that service users do not participate in decisions systematically, although policies, guidelines and laws providing that service users should be offered an active part in decision-making with regard to their care and treatment.*

Originality/value – *Although it is known that service users would like to have more influence, and that methods like shared decision-making are recommended to empower service users and improve their decision process, research on these matters is limited. The findings indicate that service users do not participate in decisions systematically, even though policies, guidelines and laws are in place stipulating that service users should be offered an active part in decision-making with regard to their own care and treatment. The results of this project bring improvement opportunities to light.*

Keywords *Mental health, Recovery, Shared decision-making, User participation*

Paper type *Research paper*

Introduction

Traditionally, service users of mental health care (hereafter referred to as *service users*) did not have an obvious role in decision-making in psychiatric care (Moxham *et al.*, 2017). In the past, mental health professionals like doctors, nurses, hospital staff and orderlies (hereafter referred to as *professionals*) were the ones who made decisions about most aspects of a service user’s daily life regarding choices of treatment and any other interventions. Goals and plans for treatments were not individually negotiated or discussed with service users, but more often made according to the rules and regulations of a given institution.

Maria Bendtsen Kronkvist is based at the Department of Clinical Science, Umeå Universitet, Umeå, Sweden. Patrik Dahlqvist Jönsson is based at the Region Halland, Halmstad, Sweden. Karl-Anton Forsberg and Mikael Sandlund are both based at the Department of Clinical Science, Umeå Universitet, Umeå, Sweden.

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This regime, which included mental hospitals, was highly custodial. A general societal trend in most Western countries toward greater participation of individuals in many aspects of life means a stronger position for patients, a trend that has also been reflected by legislative reforms. In modern mental health care, service users are supposed to participate actively, and are seen as the most important actor involved in decision-making with regard to care planning and goal-setting decisions, thereby gaining control of their own recovery process (Whitley *et al.*, 2012). Recent Swedish national guidelines and various legislative initiatives state that it is important that service users in psychiatric care, as well as in other domains of health services, participate in the planning of their treatment together with professionals (National Board of Health and Welfare, 2018), and this participation is an important feature of recovery-oriented services (Härter, 2017). The Swedish Social Services Act states that when a service user needs interventions and support, they are supposed to actively participate in the planning and decisions made about such interventions (Social services act, 2001, p. 453).

To facilitate practical application of service user participation, shared decision-making is recommended in, for example, the National Guidelines for Schizophrenia (National Board of Health and Welfare, 2018). Shared decision-making is considered to be a central component in recovery-oriented mental health care (Slade *et al.*, 2012; Slade, 2017) and can be described as an interactive process between at least two individuals (service user and professional) who share information and opinions, where both the patient's preferences and the professional's responsibilities are discussed, and where, finally, the parties involved agree on a course of action (Towle and Godolphin, 1999).

There is evidence indicating that service users are willing to participate, and that they wish to have more information about their treatment, care and greater influence over their situation (Hamann *et al.*, 2005; Clarke *et al.*, 2015). For instance, service users wish to participate in decisions (Dahlqvist Jönsson *et al.*, 2015) and professionals recognize this desire (Chang *et al.*, 2021). Gyamfi *et al.* ((2020) emphasise that both service users and professionals agree that the involvement of service users in decisions concerning their planning and care is an ongoing process that accords with recovery-oriented practice.

Although laws, guidelines and policies recommend service user participation in decision-making, studies have shown that there is a gap between that which is recommended and clinical practice (Stomski and Morrison, 2017). The service user point of view is still scarce, which is why service users need to be allowed to express their views regarding participation in decision-making (Kronkvist Bendtsen *et al.*, 2022). The aim of this study is to describe participation in decision-making among service users with severe mental illness.

Methods

The study was conducted at two separate *Homes for care or residence* (HVB) in Sweden. HVB homes provide treatment and/or focus on care, support and education (IVO (Inspektionen för vård och omsorg) (the Health and Social Care Inspectorate), 2022). The two HVBs in this study had 29 and 30 beds, respectively, for adult service users (18 years and older) with mental health problems, substance use disorders or criminality. These service users are offered care in the form of monthly contracts up to a period of several years by social services, the Public Health Agency, the Swedish Prison and Probation Service and sometimes through cooperation among these authorities. The majority of service users stay at HVB voluntarily, although some are placed by contract as part of involuntary care, following the provisions of the Act on Compulsory Psychiatric Care (Act 1991: 1128). However, these service users are under no physical restraints during their stay at an HVB. If they deviate from the HVB, the psychiatrist in charge of the compulsory care is notified. Depending on the psychiatrist's assessment of the overall situation, a renewed episode of in-patient compulsory care might follow.

Participants

The inclusion criteria for this study stipulated that participants had to be adults (18 years or older) and that both male and female service users would be included. Participants must have lived for at least one month at an HVB and suffer from mental health problems and/or substance use disorders. Participants were included if they volunteered to take part regardless of whether they were at the HVB voluntarily or involuntarily, and regardless of diagnoses. There was no participant dropout in this study, although on one interview occasion a participant left the interview session before it was finished. This incident was followed up by the staff at the HVB. It turned out that the participant had left for personal reasons, and not for any reason connected with the interview itself.

All service users at the HVBs were informed by a public billboard about the aim of the study, and the day, time and place for interviews. The participants were asked personally to participate in the study two weeks before the interview was conducted. The participants who came to the interview were given a letter containing information and an informed consent form to be signed and returned to the researcher. The researcher also requested verbal confirmation to ensure voluntary consent. Three focus group interviews (including four, five and five participants) were conducted at different times in a secluded room at the HVB. The participants were men and women aged 23–46 years who had been at the HVB between two months and two years. Self-reported diagnoses included psychosis, personality disorders, attention deficit hyperactivity disorder (ADHD) and substance use disorders (Table 1). Participants had been both voluntarily and involuntarily referred to the HVB; for legal reasons particular to Sweden, we did not ask them to disclose how they had come to be in the HVB (see also Limitations and Strengths).

Study design

A qualitative approach was applied during the focus group interviews, using a semi-structured interview guide, as the following, developed by the researchers, containing seven basic open questions in concordance with the aims of the study. The interview started with an open question that allowed the participants to reflect upon the subject. Relevant areas for decisions in this context were planning of daily activities and treatment options. During the interviews, follow-up questions were asked for further clarification. A co-researcher took notes during the interviews.

Welcome. We are about to conduct an interview, and I would therefore like to explain what this interview will focus on and what its topic is. This interview will focus on participation and by that I mean taking part in decision-making, deciding about things.

When a planning document is to be prepared or changed, decisions have often to be made concerning interventions that are to be applied. This could concern daily activities, treatment interventions, care or other type of interventions in daily life. I should therefore like you to think about such a situation, e.g. when such a plan is going to be prepared, revised or readjusted:

1. Could you start by telling me how it works?
 - Can you tell me about how it went the last time your plan was updated?
2. How do you know about or how are you aware of which interventions were to be included in the plan?
 - Your request?
 - How did you present your thoughts and ideas?
 - How did you know what interventions to choose?

Table 1 Demographic data of participants (*n* = 14)

<i>Characteristics</i>	<i>No.</i>
<i>Mean age (range) in years</i>	33 (23–46)
<i>Sex</i>	
Men	8
Women	6
<i>How long have you been in this HVB? (in months)</i>	
1–3	6
4–6	3
7–9	1
10–12	2
12 or more	1
Missing answer	1
<i>Background and cause of placement, self-reported</i>	
Some participants gave more than one reason for placement, so numbers do not add to 14	
ADHD	2
Criminality	5
Mental illness	2
Substance abuse	4
Trauma	1
Missing answer	3
<i>Diagnosis or diagnoses, self-reported</i>	
Some participants listed more than one diagnosis, so numbers do not add to 14	
ADHD	5
Antisocial behavior	1
Anxiety	1
Asperger syndrome	1
Autism	1
Bipolar disorder	2
Borderline	1
Depression	1
Narcissistic disorder	1
Nontypical autism	1
Personality disorder	1
PTSD/trauma	1
Schizoid personal disorder	1
Self-harming behavior	1
Sociopath	1
Substance abuse disorder	1
Missing answer	3
<i>Have you been placed at a similar institution before?</i>	
Yes	6
No	6
Missing answer	2
<i>If yes. How many institutions, or how many times have you been placed in this one or another one?</i>	
1	2
2	2
3	1
4 or more	1

Source: Table by authors

- For example, activities of daily living, activity, treatment method
3. Can you give me an example of a situation you were in when a decision was to be made?
 - With whom? Who was involved?

- When?
 - Where?
 - How often did this happen?
4. Have you ever felt that you wanted to change a decision?
- What happened then?
 - How did it happen?
 - What was the result?
5. What does it mean to be involved in decision-making for you as a person?
- Could you describe a situation in which you experienced participation?

Our focus was on planning documents up until today. I should now like you to tell me about other situations regarding participation here at the HVB. One such example could be health-care interventions, e.g. whether you meet with a doctor and decide which medicine to take. Another example can be when you meet your contact person at social services and a decision is discussed about extended placement or closure:

6. I should like you to tell me about how you experienced participation in such a context.
- Could you describe the situation?
7. What does participation in care mean for you?

Supplementary questions

Can you tell me more about ...?

How did you do...?

How did you feel?

What did you think?

(Table by authors)

A pilot interview was carried out (Polit and Beck, 2012) and analyzed by content analysis. The results indicated that the interview guide worked as intended. These results are not included in this study.

The interviews were conducted by the first author, and took place in 2017 and 2018. The interviews lasted for about 50min and were audio-recorded and transcribed verbatim. After analyzing data collected from two focus groups, we decided that a third focus group interview would add important information. After this third interview, the researchers decided that they had reached data saturation which signaled that data collection could cease.

Analysis

Data were analyzed, coded and discussed using latent content analysis (Graneheim and Lundman, 2004; Graneheim et al., 2017). The program Atlas (Atlas.ti, Mac Version 9.1.3, 2022) was used, and data were shared with the coauthors, through the analysis process, to increase accuracy. To get an overall sense of the transcripts, the interviews were read and listened to several times and meaning units were identified. Meaning units were then condensed to extract the essence of the text without affecting the meaning. The condensed text was abstracted in codes, where those with similar content were grouped together into subcategories. Subcategories with similar content resulted in four categories. These categories were then abstracted and interpreted into two themes (Table 2). By using

Table 2 Results from content analysis based on the methods of Graneheim and Lundman (2004) and Graneheim *et al.* (2017)

Theme	<i>Service users' involvement in decisions is hampered by the professionals' approach</i>		<i>Adequate information and experience of participation means greater empowerment</i>	
<i>Category</i>	<i>Insufficient influence in decision-making processes</i>	<i>Professionals' way of meeting and treating service users affects the individuals' decision-making abilities</i>	<i>Involvement – a prerequisite for participation</i>	<i>Service users' own responsibility in decision-making</i>
<i>Subcategories</i>	Decisions about (but without) the service users	Professionals' engagement affects service user's self-esteem Service users need to assert their right to correct treatment	Request from the service users for clearer information about rules and consequences Real influence and involvement in the decision-making process	Previous experience from other care providers influenced participation Support the service users so that they could make decisions and achieve greater empowerment
	Lack of influence in decision-making	Staff often refer to others when service users seek answers	The meaning of participation when a service user signs a contract	The service user has to take active responsibility
	Decisions that were not complied with resulted in a sense of insecurity	Luck was a factor that influenced the service users' experience of participation	Service users' impact on the environment at HVBs	

Source: Table by authors

content analysis, it was possible to present results and draw conclusions, based on the participants' experiences (Table 3, examples from the analysis).

All authors were involved in data analysis. The team consisted of one female and three male authors, including one doctoral student and three clinical researchers.

The study was granted ethical approval by the Regional Ethical Review Board in Stockholm 2017/1068-31.

Before the participants consented to take part in the study, we made sure that they understood the aim and essence of the study. It was important that they understood that participation was truly voluntary and that if they declined there would not be consequences for their care at the HVB. Confidentiality was also discussed and the researchers promised not to convey information obtained during the focus group interviews to staff members at the HVB. With these precautions, the risk for harming the participants were seen as minimal.

All participants had the opportunity to talk freely in the room. The researchers who conducted the interviews are trained in the method and have long experience of working in the clinical field. We were prepared for the possibility of incidents during the interviews, and staff who worked at the HVB knew of the interviews and were prepared to come to the interview room on short notice to intervene if needed.

Results

The analysis resulted in two themes: *The service users' desire for more involvement in decisions is hampered by the professionals' approach* and *Adequate information and experience of participation means greater empowerment*. Each theme consists of two categories named in *underlined bold type* and each category contains several

Table 3 Examples from content analysis based on Graneheim and Lundman (2004) and Graneheim et al. (2017)

Meaning unit	Condensed meaning unit	Code	Subcategory	Category	Theme
2p2: No, I've only had one meeting and we agreed and that's what I have told her who is a nurse is that I agreed with the doctor and you do not have to go in and meddle with it, and then it will be right again, then a week goes by and then she's been there again	Had a meeting with the doctor, agreed. The nurse has since made changes, I as a patient have not received information	Changes without information	Decisions about (but without) the service users	Insufficient influence in decision-making processes	Service users' involvement in decisions is hampered by the professionals' approach
2p1: That's what I'm saying, it doesn't go any further than them writing it down. There will be nothing anyway so you get tired of coming up with ideas.//..//For that, it leads nowhere	Suggestions that come from clients are written down, who are tired of coming up with ideas. Leads nowhere	Lack of influence by users	Lack of influence in decision-making		
1p3: Yes, I have tried to understand it, what is the problem, what is it that makes me come back to it	Understand the problem, why do I go back	Find insight	Service user has to take active responsibility	Service user's own responsibility in decision-making	Adequate information and experience of participation means greater empowerment

Source: Table by authors

subcategories named in *bold type*. Examples from the condensed meaning units are marked by *italics*. The participants are identified in the quotes with anonymous codes.

Service users' involvement in decisions is hampered by the professionals' approach

The participants reported many levels of involvement in decision-making, from a total lack of involvement in decisions to participation in both planning and decision-making regarding, for example, interventions.

Insufficient influence in decision-making processes. In the subcategory *Decisions about (but without) the service users*, participants described situations in which they felt powerless with regard to decision-making, e.g. in planning activities and treatment methods. These *decisions could be made by somebody else without informing the service user*, by both staff and the contact person at social services:

2p2: You can make a decision with the doctor and the nurse present,//..//then it could be changed//..//I ask – What is this?//..//The nurse answers –//..//I have done this and this, and I'm like – you're not a doctor, this is not what we agreed about. If there are changes, I should be informed before.

Lack of influence in decision-making was mentioned by the participants, who, even if they felt that the professionals understood them and let them participate in decisions, *they did not have a "real" role in the decision-making process*. Sometimes they were asked about their feelings, wishes and thoughts when the staff updated central documents for planning,

but they felt that *they were only asked about these things to make it look good*. Some of the participants were *not familiar with what was written in their planning documents*:

1p1: It may be that people listen and perhaps they even understand, but in the end, they don't base decisions on that.

Decisions that were not complied with resulted in a sense of insecurity. Decisions and promises that service users made together with the staff could sometimes be broken, which made the service users feel unimportant:

2p2: It feels like everything keeps changing all the time, and poor information about, for example, a cancelled meeting. . . .//you can never really trust that it will be as planned.

Professionals' way of meeting and treating service users affect the individuals' decision-making ability. The fact that *professionals' engagement affects service users' self-esteem* was expressed by the participants questioning the professionals' engagement and interest in the service users' situations. On the one hand, the *service users did not want the professionals to read their patient records* and be "judged" by their history. On the contrary, the participants experienced a *lack of interest from the professionals*. *Service users needed to assert their right to correct treatment, as they were not always trusted and taken seriously*:

1p2: Who are you? You're just a piece of paper with black ink on it, they don't know who I am, they haven't read my history and the reason why I'm here.

The participants experienced that *the staff did not have time to sit down and talk*. *Staff often referred to others when service users sought answers* to minor as well as major issues. There was often a sense of the *professionals not wanting to stand up for their own decisions*:

1p2: Staff says – it's not me who has taken that decision, so I can't. . . .//And I'm like – are you not working here? Are you guys not one unit?

Findings show that *luck was a factor that influenced the service users' experience of participation* in decision-making. Having luck meant that service users had someone who listened to their wishes and that the professional was involved in the service user's situation. *It was luck if service users met "the right" professional who could respond to their needs the right way*. The participants said that *the matching process between the professionals and the service users was like a lottery*:

1p1: Perhaps only one member of the staff knows how to approach and treat Liam [NB: a fellow resident in the HVB] the right way, who knows what Liam needs. . . .//when Liam feels really bad and low. If Liam turns instead to another staff member, he won't get the same treatment.

Adequate information and experience of participation means greater empowerment

This theme is about service users experiencing a lack of influence and at the same time being aware that service users have to take active responsibility – one cannot just let others do the job if one wishes to participate in decisions.

Involvement – a prerequisite for participation. There were urgent *requests from the service users for clearer information about rules and consequences* when service users were meant to have no influence on decisions. There was *an understanding of why some rules exist*, although it was sometimes hard for the service users to accept it. Sometimes the *service users felt that the professionals used rules as punishment*. This feeling concerned rules, medical decisions, how to apply for leave, and other things that had various consequences for the service users:

3p2: So if you look at it like this, you're not here voluntarily, if you go on leave without applying for it, two weeks back in time, even for going to a funeral or so I guess, then it's like – NO.//. . //that makes it some kind of compulsion.

Although sometimes experiencing powerlessness, as expressed above, participants said that there were situations in which *they were given an opportunity to take active part from the beginning* of their planning. Such circumstances meant that service users experienced *real influence and involvement in the decision-making process*, planning and treatment – *a process based on dialogue and discussion between the service user and the professional*:

2p3: I went through a pretty rough abstinence phase when I came here at first, so I wanted to take part in as much as possible, instead of sitting by myself and pondering over things.

The meaning of participation when a service user signs a contract, which includes *the power to sign or not to sign a paper*, contract or otherwise, could mean that service users either were or were not involved in decisions. The service users perceived this as “power,” which they sometimes used to claim their rights:

1p2: You as a client can actually go and tell the staff – now I would like to change my plan because it's not working.//. . //And I am not going to go and take part in treatments before my plan is changed.

Service users' impact on the environment at HVBs was defined as *service users being able to participate in decisions* during regular consultation meetings which were voluntary for all users of the HVBs. These meetings gave opportunities for one to make one's voice heard in the hope of effecting changes. The participants said that *this forum gave them a feeling of security* and that *the service users dared to speak out about things*:

3p1: Earlier, some were using drugs, and there were fights [. . .] But now this has changed, they [NB: the staff after a discussion at the forum] have finally taken care of the problem and introduced tougher rules.

Service users' own responsibility in decision-making. It was important for participants to *play an active role in decision-making with the guidance of the professionals*. Having an active role and being aware of one's rights to participate was linked to the subcategory called *previous experiences from other care providers influenced participation*. The participants stated that it was important that the professionals *supported the service users so that they could make decisions and achieve greater empowerment*:

2p2: I really believe in what he [NB: the contact person] says, if you do things outside [NB: out of the HVB's environment] that you can practice doing something that is fun in a sober state and really feel it.

Professionals should guide and support service users, but in the end, it is *the service user has to take active responsibility*: “If change is to take place it's my responsibility,” as one of the participants said:

1p2: The only one who can make amends is you, it's not the staff. You could get support//. . //, but you can't change if you don't want to do it yourself.

Discussion

The findings of this study describe participation in decision-making by service users with severe mental illness. The participants represent a vulnerable group of persons with severe mental illness that is not often subject to research.

The first theme, *Service users' involvement in decisions is hampered by the professionals' approach*, emphasizes that service users seem to experience *lack of influence on decision-making*, even though research suggests (and policy documents, guidelines and laws

stipulate) that service users should be offered an active part in decision-making with regard to their care and treatment. A recent meta-synthesis (Stomski and Morrison, 2017) demonstrated that although participation was recommended by, for example, national guidelines, service users' participation was not applied in clinical practice. Huang *et al.* (2020) have also pointed out that even though shared decision-making has been identified as an important component of recovery, it is not routinely implemented.

This study shows that service users did not participate in a structured way in decision-making processes, and that their participation was often related to luck in meeting the right professional, which was a factor that influenced the service users' experience of participation in decision-making. The element of luck in therapist assignment seems to be generally acknowledged, and it is striking that the element of luck is not seen in terms of deprivation of decision-making.

Le Boutillier *et al.* ((2015) emphasize that important components of personal recovery are autonomy and decision-making. The present study shows that sometimes a service user experienced their influence on decision-making as disingenuous, that is, as something just for show. However, the second theme, *Adequate information and experience of participation means greater empowerment*, indicates that there were moments and circumstances in which service users experienced real influence and involvement in the decision-making process, but that these occasions were not structured in such a way as the service users desired, or as is recommended by guidelines.

The participants in the study said that they felt that being involved in decisions meant, for instance, that they had the right to stop taking prescribed medication, and explained that this was a way to use one's rights as a patient. Exercising influence in this absolute way can of course have negative consequences for the individual and also for people in his or her surroundings. This type of influence does not come close to sharing the decisions. Similar results were revealed in Gyamfi *et al.* ((2020), a study concerning service users who experienced their involvement in decision-making as merely the ability to say "yes" or "no," or by pointing out the negative side effects of medications or other treatments and then having the opportunity to try other interventions. This kind of involvement in decisions has to do more with basic human rights than with playing an active role in decision-making.

The findings indicate that service users want professionals to engage more fully in recovery-oriented work which means that professional would support the service users so that they could make decisions and achieve greater service user empowerment. Haugom *et al.* ((2020) call for training professionals in the recovery process to gain more knowledge about it, a view also supported by Kronkvist Bendtsen *et al.* (2022). Castro *et al.* (2016) emphasize that if service users are to be empowered, both patient participation and patient centeredness are necessary. These results indicate that there is a need for properly structured methodology and concrete methods for professionals to work together with service users. Implementing shared decision-making, which is a structured way of involving service users in decision-making processes (Towle and Godolphin, 1999), may affect both the desire of service users for more structure and the need of professionals for more practical tools to help them involve service users in a decision-making process. Shared decision-making implies that the preferences of both professionals and service users are systematically taken into consideration. A study by Hamann *et al.* (2020) reveals that even patients with severe mental illness benefit from using shared decision-making. The participants in this study would undoubtedly also benefit from the application of this kind of method.

It would be of interest to compare the results of this study with the results obtained from other settings, like in-patient wards. The professionals' experiences of service users' participation in decision-making are also of interest. Studies have showed that skills in shared decision-making can create the opportunity for professionals to work with users in a structured way (Kronkvist Bendtsen *et al.*, 2022). Perhaps this structured way to handle

decision-making can mean greater participation in the decision-making process for the service users, and also minimize the influence of luck.

Limitations and strengths

The limitations of this study include the fact that data collection was done in 2017/2018 and therefore are not up to date. However, no overall changes in policies and guidelines for service users at HVBs in Sweden have taken place recent years, and there is no reason to think that the results reported here would be any different if the data had been collected more recently. The COVID-19 pandemic greatly affected the entire community, but everyday life at HVB's remained the same except that face masks and greater physical distance were temporarily introduced.

The transferability of the study is limited as a consequence of the method applied and a small sample size. The total number of 14 participants can be seen as a limiting factor, because important experiences may have been omitted. On the contrary, the participants represent a diversity of characteristics, for example, they have experienced both psychiatric inpatient and outpatient care.

The participants were not asked whether they had been placed voluntarily or involuntarily, which means that the result cannot be analyzed from this perspective. The participants in the focus groups consisted of service users who were placed both voluntarily and involuntarily. However, the aim of this study was to describe participation in decision-making by service users with severe mental illness in an HVB setting, where both voluntary and "convicted" service users live together. The questions asked to the participants were about decisions made at the unit, and how the participants experienced influence in their care. Decisions about the content of care are made regardless of a service user's voluntary status. It can be assumed that a service user who stays at an HVB involuntarily might have somewhat lower expectations of their participation in decision-making, but this was not obvious during the interviews. Questions about differences between those at an HVB voluntarily and involuntarily would of course be very interesting, but would have required a different study design.

When two focus group interviews were performed and transcribed, the research group observed that one of the interview groups consisted solely of men. Therefore, a third focus group interview was conducted that included both men and women. This third interview resulted in a certain degree of redundancy, which is why sufficient saturation was assumed. The interviews were done in Swedish and quotes were translated into English. Although we worked carefully with translation, it is possible that important nuances in the material have been lost.

There is a risk for bias in the sample. We do not know whether service users who were satisfied with their participation in decisions were more or less prone to take part compared to participants who were dissatisfied. However, this potential risk is an inevitable problem in all studies designed to respect the voluntariness of persons involved in research.

A strength of this study is the setting. Research conducted in HVB (or similar facilities) is rare, as is research concerning this vulnerable group of people who are treated in this kind of institution. We believe that the participants in this study are fairly representative of persons so treated in Sweden, which means that the results might be considered transferrable to other countries with similar mental health and social services systems.

Conclusion

This study focuses on decision-making in a branch of mental health services that specializes in a vulnerable group of service users. The situation and perceptions of this group can only be described when research is conducted in these settings. The result highlights that service users' involvement in decisions seems to be hampered by the

approach of professionals, indicating that it is important for professionals to be aware of the power that comes with their role.

This study also demonstrates that adequate information and prior experiences of participation have a great impact on participation in decision-making. Service users with more extensive experience are more likely to be involved and participate in decisions about their care than service users who have less experience. This information points to a need for individual adaptation of routines in situations in which decisions are to be made.

Service users wish to take an active role in decision-making, but we did not detect that they had any particular ideas about how to fulfill that wish. They do not seem to have been presented with the method of shared decision-making, which is a bit surprising because this method had been put forward in official guidelines well before this study. On the contrary, a recent nationwide survey demonstrated that implementation has been uneven and inadequate in Sweden (National Board of Health and Welfare, 2022). We think that measures to increase the awareness of the shared decision-making method among professionals, as well as among service users, might improve the partnership between staff members and service users when deciding on the content of care.

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Corresponding author

Maria Bendtsen Kronkvist can be contacted at: maria.bendtsen.kronkvist@umu.se

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