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User and carer involvement in social work education: reasons for participation

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ABSTRACT

In many countries, user involvement in social work (SW) education is common practice, while in other countries, initiatives for inclusion are currently expanding. No matter how far the progress of user involvement in education has come, issues on clarity, sustainability and accountability need to be addressed. In this paper, users' reasons for wanting to participate in SW education and the way they define their potential contribution are explored. These experiences can provide important information contributing to sustainable, meaningful, and accountable collaborations between users, university staff and students. Participants ($n = 33$) answered a questionnaire including demographic data and four open-ended questions about their expectations of participation in a SW programme at the University of Dalarna in Sweden. The results from the open-ended questions were analysed using qualitative content analysis. Results show that users' main reasons for wanting to get involved were to contribute through sharing their lived experience of SW education, to help improve services and also to obtain respect for their own personal knowledge and experience. The respondents described themselves both as carriers of valuable knowledge and as accountable experts on the subject.

As user and carer involvement in social work (SW) is increasing, and SW education has developed and in several countries become widely accepted, concern has been raised that the involvement should be meaningful and of good quality. The primary purpose of user involvement needs to be clarified and issues related to the role of users and their perceptions of what they can contribute need to be further explored. This paper presents a project designed to involve user and carer knowledge in SW education at Dalarna University in Sweden. The project aims to prepare the students for an anti-discriminatory and empowerment-oriented social practice by involving service users in teaching, seminars, preparation for practice learning and in assessments.

The users all have experience of mental illness and the carers have experience of being carers of someone diagnosed with mental illness. The focus here is on investigating these users' and carers' reasons for wanting to participate in SW education, and how they define their potential contribution.

Background

User involvement in SW education is growing across Europe, especially in the UK and various Eastern European countries (Agnew and Duffy 2010; Rhodes 2011; Robinson and Webber 2012). However,

user involvement in SW education in the Nordic countries is still limited (Askheim 2012). This lack of involvement may partly mirror differences in government policies. In the UK, for example, every accredited SW faculty receives financial contributions for service user involvement in the educational process (Rhodes 2011). The increase in user involvement can further be explained by incentives from the user movement (Waterson and Morris 2005) which has been influential in raising awareness and in the advance of a broader view of knowledge (Brown and Young 2008). The argument that user involvement can improve service users' outcomes in services has also influenced the strategic development of user involvement in SW education (Anghel and Ramon 2009).

User involvement in SW education is described as consistent with the SW values of respect, independence, empowerment, and anti-discriminatory practice (Beresford 2003). The most common type of user involvement in SW education is through some kind of teaching activity or programme delivery (Agnew and Duffy 2010; Brown and Young 2008; Gee, Ager, and Haddow 2009; Robinson and Webber 2012). In these initiatives, service users and carers give personal testimonies or present personal histories (Agnew and Duffy 2010; Rhodes 2011; Robinson and Webber 2012), act as co-trainers and facilitators of workshops (Brkic and Jugovic 2009; Brown and Young 2008) and collaborate on projects (Agnew and Duffy 2010; Brown and Young 2008; Urbanc, Radovic, and Delale 2009). A number of positive results from these initiatives have been described for students, university staff, and users and carers. User involvement can offer improved experience and understanding of what it means to be a client (Bornarova 2009) and of the role of SW in specific situations (Agnew and Duffy 2010), which results, for staff, in increased confidence and in being better prepared to assume a professional role (Agnew and Duffy 2010). User involvement encourages the process of normalization of disability in a society where being disabled is connected to stigma (Zaviršek and Videmšek 2009). Users and carers benefit personally by making friends, being involved in a group of other users or co-researchers, becoming empowered, and having increased confidence (Brown and Young 2008; Matka et al. 2010; Zaviršek and Videmšek 2009). The benefits can also be practical, such as learning new skills, having a valued role, and possibly earning money (Matka et al. 2010; Warren and Boxall 2009; Zaviršek and Videmšek 2009).

On the other hand, initiatives of user involvement in SW education also highlight challenges (Fenghe 2010; Zaviršek and Videmšek 2009). There is still limited evidence that involvement leads to changes in SW education or practice or indeed to significant benefits for the client and improvement in their situation (Brkic and Jugovic 2009; Carey 2009; Gallagher, Smith, and Hardy 2012; Rhodes 2011; Robinson and Webber 2012; Rummery 2009). Some studies even suggest that user involvement may increase social inequalities by justifying and promoting hegemonic agendas (Carey 2009; Carr 2004; Levitas 2005). Several studies illustrate that user involvement in SW education is not yet seen as a real activity or as increasing capacity, which raises issues of sustainability and funding (Agnew and Duffy 2010; Brkic and Jugovic 2009; Brown and Young 2008; Rhodes 2011). Furthermore, it is argued that initiatives on user involvement have mainly been developed on an ad hoc and inconsistent basis (Minogue et al. 2009) and that there is a need for further clarity on how to involve user knowledge, what the expectations on the users and carers are (Gregor and Smith 2009) and what kind of training and support users and carers need to participate in SW education (Beresford and Boxall 2013; Gallagher, Smith, and Hardy 2012). User involvement in education can be problematic if involvement is under the control of the academy and serves the needs of the organization more than empowering the client (Beresford and Boxall 2013; Gallagher, Smith, and Hardy 2012). An exploration of personal reasons why users get involved in education and their perceptions of what they can contribute may be an important clue to clarify a sustainable and contributing involvement. Users willing to participate and contribute need to be cultivated and supported according to their needs and expectations (Brown and Young 2008; Gregor and Smith 2009). In this article, users' reasons for wanting to participate in SW education and their ways of defining their potential contribution are explored. These experiences can provide important knowledge contributing to sustainable, meaningful and accountable interactions between users and carers, university staff, and students.

Aim

The aim of this study was to explore service users' and carers' reasons for taking part in SW education, and their ways of assessing their user knowledge or user expertise.

Method

The participants were recruited through an advertisement in two local newspapers. The advertisement invited people with experience of mental illness or of being the carer of someone with a psychiatric diagnosis. The advertisement described that Dalarna University searched for participants for an experienced panel, which aimed to be a support and advisory body in SW education and research. Furthermore, it was described that the panel participants would be offered training in social psychiatry research methods during eight sessions over a period of three months. Participation in the experience panel was remunerated. Conditions for participation were user experience, interest in knowledge and research and basic knowledge of English. Questions and interest were asked to be sent via e-mail. People who emailed interest were invited to the information meeting. The information meeting, held by the researcher and author of this article, took place at Dalarna University and was also streamed to reach as many interested as possible.

The information meeting included information about how Dalarna University wanted to establish an experienced panel to expand the concept of knowledge to students, teachers and researchers in SW. Clear information according the uncertainty about the duration of the project was also given. No assurance of assignments after the project period could be promised.

During this information meeting, an anonymous voluntary questionnaire was distributed. Brief written information on the questionnaire outlined the voluntary nature of participation, the purpose of the questionnaire, and the planned use of the data. The respondents were instructed not to write their name on the questionnaire and to leave the questionnaire at a collection point in the room, either filled in or blank.

The questionnaire contained both multiple-choice questions and open-ended questions. The five multiple-choice questions were concerned with demographic data: gender, age, type of experience, educational level, and occupational status. The four open-ended questions were concerned with the respondent's expectations of participation in a user panel. The questions were formulated as follows: 'What are your reasons for coming to this information meeting?', 'What kind of knowledge can you contribute?', 'What kind of activities would you prefer to be a part of at Dalarna University?', and an open question: 'Do you have any other comments?' The space provided for answering the open-ended questions in the questionnaire was 1.5 pages in total, and the majority of the respondents had used up all the space; several had also continued their answers in the margins of the questionnaire. The first draft of the results from the questionnaire was given to the respondents to read six months after the panel had started. At this point the respondents gave their written informed consent.

Sample

Of 47 participants in the meeting 33 participants answered the questionnaire (Table 1). The majority of the respondents had own experience of mental illness (15 women and 6 men); 4 were close relative (parent or child) to a person with mental illness; and 8 had both own experience and were close

Table 1. Demographics of the participants ($n = 33$): gender and user experience.

	Women	Men
Own experience of MI	15	6
Close relative to a person with MI	4	0
Own experience and related to a person with MI	8	0

relative to a person with mental illness. The respondents' age ranged from 21 to 64 years. More than half of the respondents (*n* = 19) were employed in the open labour market, 10 were receiving disability allowance, and 4 were employed at government-run day care centres. All but one had completed 9 years of elementary school, 24 had completed a gymnasium (college) degree, and 6 had a university degree.

Analysis of the data

Conventional content analysis was used to analyse data (Hsieh and Shannon 2005). The answers from the open-ended questions were transcribed verbatim, creating a total of 31 pages of typed, single-spaced text. In order to gain a sense of content understanding, the analysing started with reading all transcribed data inductively several times. Then, data were read word-by-word to derive codes by first highlighting words from the text that appeared to capture key thoughts or concepts. During this process notes were made of impressions, thoughts, and initial analysis. During the process preliminary labels for codes emerged from the text that was reflective of more than one key thought. Thereafter, codes were sorted into categories. These emergent categories were used to organize and group codes into clusters (Patton 2002). Then definitions for each category, subcategory, and code were developed and the relationship between them was defined based on their concurrence, antecedents, or consequences (Morse and Field 1995). The analysis also included a comparison between answers from participants with their own experience of mental illness and answers from participants responding as carers.

Findings

The participants gave positive feedback on the project of starting a user panel and express enthusiasm for the project. One respondent wrote, 'Very positive initiative! Good to enlist the help of users.' Another noted: 'Not to make use of user knowledge would be a major flaw. On reflection, pure madness.'

The analysis of the results illustrate how the reasons for joining a user panel are rooted in a desire to contribute with experiential knowledge, but also to contribute to improvements in psychiatric services and in society in general regarding stigma and ignorance. In the analysis two overlapping dimensions of reasons for joining emerged; the first *knowledge contribution,* explains the broad experience-based knowledge the respondents possess and want to convey. The second dimension, *reducing stigma*, reflects the respondents' desire to contribute to improvements in attitudes and knowledge in psychiatric services, in society in general and also within themselves Figure 1.
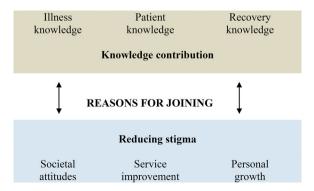

Illness knowledge	Patient knowledge	Recovery knowledge
Knowledge contribution		

↕ **REASONS FOR JOINING** ↕

	Reducing stigma	
Societal attitudes	Service improvement	Personal growth

Figure 1. Core categories and subcategories of reasons for joining.

These two dimensions of reasons for joining a user panel are intertwined. In the following we take a closer look at these dimensions.

Knowledge contribution

Knowledge contribution covers the various types of knowledge that respondents considered themselves to be carriers of, and wanted to convey. A striking similarity among the 33 respondents was a desire to be respected as carriers of knowledge. They described the knowledge to be gained from their experience as a currently 'untapped resource' and outlined experiences of having an illness and receiving support from social and psychiatric services. They further described their own knowledge, and that of others, as 'real knowledge', 'knowledge as a key for improvement', and a 'large bank of knowledge' that had not been utilized in social services or psychiatric care during the periods when they were receiving care or support.

Patient knowledge

The most common knowledge mentioned by the respondents were the experience of being a patient in psychiatry or social services. Many of the respondents stated that the experience of receiving psychiatric or social services also was one of the most important contributions that they could make to SW education. One of them expressed this as 'a glimpse of how it feels to be on the receiving end'. The users and carers emphasized the effects that service perspectives, routines, staff, and decision-making had on their lives. Some comments were positive, with respondents wanting to describe the positive services they had received. These comments were related to certain staff attitudes within psychiatry or social services. However, the majority of the responses about the experience of receiving care were negative. Many of the respondents described how they wanted to enhance the knowledge that staff have of mental illness by contributing examples of what 'a good treatment is' in general, as well as what they believed were good responses to people with the same diagnosis as their own. Many users felt 'misunderstood' and a few, mainly carers, felt 'rejected' by service staff. They wanted to contribute their experiences on how to respond to users within psychiatric care and in the social services, providing 'knowledge about what is important when you are ill'. One respondent stated that she had 'insight into several generations of psychiatry', with experience both of growing up with a parent with mental illness and then later being diagnosed herself with mental illness.

Experiences of being a receiver of services also included a variety of social services, such as being in foster care, attending special schools, and receiving financial support: 'I have experience of being poor and receiving financial support.' One respondent wrote: 'I have experience of growing up in a dysfunctional family with lots of support from the social services.'

Illness knowledge

The second perspective on making a knowledge contribution in the SW education was that of *illness experience.* Illness experience concerns knowledge of what it is like to live with a certain illness, in this case psychosis, schizophrenia, severe depression, bipolar disorder, personality disorder, or attention deficit hyperactivity disorder (ADHD). They wanted to describe how the disease can manifest itself; 'It can be frightening at the beginning to have these symptoms' how it fluctuates but especially to provide a normalized view of people who have a mental illness. One respondent described how she wanted to 'give a human face to psychosis'. The respondents had experience of living life with these diagnoses, and of the consequences of ill health, such as symptoms and disability. One respondent stated, 'If I can contribute to a better knowledge about girls with Asperger's disease, then I am happy.' Another respondent wrote, 'I want to describe what it's like to live with ADHD.'

Illness experience also encompassed the impact the illness had on their life situation, with regard to the workplace and relationships with others. Similarly, those respondents who were carers to people with mental illness described the illness experience in terms of what it was like to be a carer to a person with mental illness and how it affected their life situation too: 'I want to tell students what it means to be the parent of a teenager with psychosis.' Another respondent wrote: 'My mother's illness affects my life situation in numerous ways.'

Recovery knowledge

The third perspective on knowledge contribution was *recovery knowledge*. This category refers to the users' knowledge of what helps in the personal recovery process. This knowledge is described separately from the knowledge of the disease. It is about how to master their mental illness but also what contributes in creating a meaningful life. Sharing this knowledge was considered important for students – future service providers who could use this knowledge to promote recovery. Another assumption was that recovery knowledge could revise service providers' opinions about the users' own capacity; 'Students need to know that recovery from serious mental illness is possible. There is still pessimism among many, that mental disorders are chronic conditions.'

Reducing stigma

The second dimension of reasons for joining that emerged in the analysis was *to reduce stigma*. The dimension relates to intended actions that may contribute to improvements of the prevailing view of mental illness in society, within psychiatric services, within research and within oneself.

Societal attitudes

The first area of reducing stigma relates to societal attitudes. Respondents described how they wanted to 'change attitudes' towards mental illness in society and 'contribute to a broader perspective on differences', describing the boundaries of normality as 'narrow' or 'unhealthy'. Others wanted to demystify their particular diagnosis, with the aim of reducing fear, misunderstandings and prejudice in the community.

Research improvement

Many of the respondents also reported that they wanted to 'contribute to future research', which in one sense related to contributing ideas on important but as yet un-researched issues: 'I want to tell researchers about what needs to be researched.' Another aspect of contribution to research concerned that users possess important knowledge that can contribute to more accurate research. Examples of activities in this area included taking part in project design, formulating questions, and finding out how to get respondents with mental illness to participate in studies: 'I think users know well if these are the right questions, if important questions have been forgotten, and how to motivate users to participate in studies.'

Service improvement

The third area of reducing stigma concerns the stigma within SW practice or psychiatry and how this could contribute to service improvements. This category is intertwined with 'patient knowledge' emphasizing experiences of being badly treated because of their mental illness and because of a lack of knowledge and experience among staff. What characterizes this category is the predominant knowledge in the services and who possesses the definition of power in the respondents' care

process. One respondent, referring to service users with mental illness, stated: 'There are so many beliefs about us.' Another respondent, who worked in psychiatry herself, described how switching sides and becoming a recipient of care was a 'frightening experience'. Many of the respondents expressed disappointment at not being heard when receiving services or care. Their thoughts and experience were neither respected nor requested by staff. They discussed how their own experience could be useful to other users and professionals.

There was a difference in response depending on whether the respondents had their own mental illness or whether they were a close relative to someone with a mental diagnosis. Respondents who were relatives emphasized the need for a carer perspective in education and research. Almost all of these respondents stated that their knowledge about their relative had not been requested at meetings with mental health professionals or social services. During treatment, the staff had failed to keep them informed about progress, future plans, and their own role in promoting the recovery process. The carers described a lack of control over and knowledge about the treatment process, and a lack of respect from the psychiatric staff.

The emphasis on user experience was, as in earlier responses, closely linked to respect. The users had not felt respected in their meetings with staff in psychiatric services. One respondent described his experiences as a 'total lack of sharing knowledge and information'; he was expected simply to receive and comply with professional advice based on professionals' expertise.

Personal growth

The third area of reducing stigma was related to the respondents' own personal growth. Participating in a user panel was understood as a way to find a meaningful activity and grow as a person. Some wrote that they now felt so much better that they wanted to 'test their own capacity'. The respondents wanted to share this knowledge with SW students and already trained staff in social and psychiatric services. The most commonly mentioned activity from both users and carers was teaching or lecturing through 'personal testimonies'; telling their life story about being ill and the care and support they had received: 'I want to tell my story to students and staff in psychiatric and social services.' At the same time, some of these answers signalled a degree of uncertainty about the respondents' own ability, due to disability or lack of experience. One respondent stated, 'I'm unusually talkative and hope that it is possible to "test" whether I can work as a lecturer.' Another wrote: 'I'm very unused to speaking to an audience, but think I could if I got some training in it.'

The respondents stated that the advertisement in the newspaper had made them 'curious' about the project and the additional training that would be offered to the panel. However, curiosity also related to gaining more knowledge themselves. A few respondents described how they saw the project as an 'opportunity to increase their knowledge' about mental illness through meeting with others.

Membership of a user panel was also described as a means to 'come out' with the illness and from experience help others to recover. One respondent stated: 'Right now, I'm at the stage where I am ready to help others and share what has contributed to my recovery.'

Some respondents seemed to have brought their own project ideas to the information meeting. These ideas illustrated activities or services that they thought were needed but had themselves missed as service users or carers, not only within psychiatric services but also in school. One example was: 'I want to be involved in starting a self-help group for young girls where they can learn that they are good enough.' Another example of an innovative idea was: 'I want to guide students in how to support children with mental illness in school settings. In this, knowledge of assistive technologies will be important.' One respondent described how she wanted to encourage the development of a methodology around the interaction between health care and families, and to call this the Relatives' Emergency Room ('Anhörigakuten' in Swedish), providing health care information for carers.

Discussion

The results from this study emphasize a twofold aim when involving service users in a concrete educational context: to enhance the education and empowering the users and carers.

According to the respondents, concepts of knowledge and the provision of a broad experience-based knowledge to students and staff is the main reason for participating. Furthermore contributing with knowledge was perceived as a meaningful activity and an opportunity to test their ability.

Suggestions for added value in SW education included positive and negative experiences of mental illness and recovery and of receiving psychiatric and social services. The personal experience of living with a mental illness was assumed to broaden the students' views of disability and recovery. Experience-based knowledge also extends beyond the contact with psychiatric services to include the experience of living with, or being a carer to someone with a disability in society, considering external and internal stigma. The users' and carers' ideas of how they could contribute correspond well to how user and carer perspectives are described from a staff or researcher's perspective in previous research studies (Agnew and Duffy 2010; Anghel and Ramon 2009; Bornarova 2009; Gee, Ager, and Haddow 2009; Robinson and Webber 2012). This relative consistency in the definition of the meaning of user expertise could, in theory, facilitate collaboration among users, academic staff, and students (Agnew and Duffy 2010). Effective user involvement in SW education is described as a developing exercise that engage users, carers, lecturers, and students for an improved knowledge-base (Leung 2011; Minogue et al. 2009). This implies that staff and students need to be encouraged to broaden their perspective on knowledge and value of the users' experiences; understanding users' and carers' contributions as fundamental for teaching SW values such as respect, independence, empowerment, and anti-discriminatory practice (Beresford 2003).

User and carer involvement in SW education also has the potential to empower the participants and promote recovery, by offering meaningful assignments and valuing the knowledge they convey. An underlying feeling among many respondents seemed to be a disappointment that their knowledge had not previously been respected. The proposed project for involvement in SW education was understood as a potential arena in which this knowledge would be requested and furthermore be respected. There might be a delicate line between seeing this involvement as an opportunity to finally 'have a say' and entering a position where such personal experiences of disrespect also must be reflected on a general level. However the users and carers are representing something more than themselves; they carry with them and bring into the educational setting a mode of knowledge. That goes beyond 'a person telling her story' – and acknowledge the user's need to share this – to its' value on a more general level. Individual users may also differ with regard to whether they want to identify themselves as service users or 'ex-service users' far into the recovery process. The disparate roles of sharing experiences of psychiatric services as a service user, and at the same time testing ability to be a credible lecturer at the university, may be confusing for both users and carers, and the students. Previous projects illustrate how university structures may be inflexible and university staff may not yet be confident with the idea of service users as colleagues (Agnew and Duffy 2010; Bornarova 2009; Skokandic and Urbanc 2009). From that perspective there is a risk that users are not given access to the role of credible lecturers and colleagues, which may in fact be detrimental to recovery. User involvement can be problematic if involvement is under the control of the academy and serves the needs of the organization more than empowering the users and carers offering opportunities for users to achieve their goals (Beresford and Boxall 2013; Gallagher, Smith, and Hardy 2012).

The respondents in this study described a need for support and training in order to assume the role of an experience-based expert in teaching and to participate in SW education. This need has been highlighted in other studies as a prerequisite for sustainable cooperation (Beresford and Boxall 2013; Gallagher, Smith, and Hardy 2012). The emotional labour of SW education on users and carers may be hard to share with academic staff and needs to be supported from somewhere else, outside academy (Gregor and Smith 2009). Beresford and Boxall (2013) argue for a more collective involvement in SW education by user organizations to avoid individual 'isolated' user

involvement under the control of the academy. Collective involvement, building upon service users' organizations and movements, may offer a more effective basis for challenging traditional under-standings of service users and to enable SW to be better informed by disability studies through service users' standpoints and knowledge. In the present project the intention was to reach a broad group of users and carers. In Sweden, the user organizations have had problems recruiting new members in recent years. This means that a high proportion of members in the user organiz-ations are older and have experience of psychiatric services further back in time.

Limitations and future research

It must be remembered that the results are based on responses to a small number of questions asked during an early stage of a programme aimed to involve user knowledge in SW education in Sweden. Consequently the participants were people who had already shown interest in user involvement in SW education. The recruitment process may further mean that the respondents represent people with stronger resources and social skills compared with the population of people with mental illness in general. The respondents' level of education reinforces this point. Still the results can poten-tially contribute to valuable knowledge to services working for service user involvement. Further studies using in-depth interviews on a broader group of service users would probably provide more credible knowledge on this subject.

　　Nevertheless this study stresses the importance of further research in the field of user involvement in SW education and practice. In the absence of a robust evidence base, there are no current primary drivers for service user and carer involvement in SW education in Sweden and many other countries. Further research is needed to move towards an evidence-based model of such involvement (Robin-son and Webber 2012). Longitudinal studies following SW students from education into employment are required to evaluate the effectiveness of service user and carer involvement in SW education. These studies could evaluate the independent effect of user involvement on social workers' work and on the outcomes for the people they work with.

Disclosure statement

No potential conflict of interest was reported by the author.

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