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Exploring the value of involving experts-by-experience in social work research: experiences from Slovenia and the UK

Raziskovanje vrednosti vključevanja ljudi z osebno izkušnjo v raziskovanje v socialnem delu: izkušnje iz Slovenije in Združenega kraljestva

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ABSTRACT

The evidence base for the methodological validity of conducting participatory research is becoming established. This article reviews the experiences of two researchers undertaking Ph.D. studies in Slovenia and UK, respectively, and considers the value of involving service users and carers in social work research. The Slovenian research involved user-researchers who developed research tools and undertook qualitative research. The first author explores the co-researchers' impact on the research process and its outcomes, identifying both individual and collective empowerment of the co-researchers. The English study involved people from diverse backgrounds, who developed a recovery training programme for carers of people with schizophrenia. The second author describes how the steering group, and the carers who participated in the programme were impacted by the research process and experienced a sense of empowerment and how they influenced the development of new knowledge through the reflexive cycle. The authors draw out the commonalities and differences in our research that add to the existing evidence base supporting the development of participatory inquiry. We conclude by affirming the value of user participation in research in leading to the empowerment of users, the development of new research perspectives, and in contributing to theory in social work research and practice.

POVZETEK

Vključevanje ljudi z osebni izkušnjami v raziskovanje se vse bolj uveljavlja. Članek je pregled dveh raziskav, izvedenih v okviru doktorskih disertacij v Sloveniji in Združenem kraljestvu, ki prikazeta pomembnost vključevanja ljudi z osebni izkušnjami v raziskovanje v socialnem delu. Slovenska raziskava vključuje uporabniško raziskovanje: ljudje z osebni izkušnjami so razvili raziskovalni proces in izvedli kvalitativno raziskavo. Prva avtorica tega članka prikaže vpliv sodelovalnih raziskovalcev na raziskovalni proces in rezultate raziskovanja s prikazom tako individualne kot kolektivne krepitev moči udeleženi raziskovalcev, poleg tega pa pojasni, kako uporabniško raziskovanje pripomore k novemu znanju. Britanska študija pa vključuje ljudi iz različni socialni okolij, ki so razvili program okrevanja za svoje ljudi s shizofrenijo. Druga avtorica

KEYWORDS

Social work; research; mental health; user involvement; participatory inquiry

KLJUČNE BESEDE

socialno delo; raziskovanje; duševno zdravje; vključevanje uporabnikov; sodelovalno raziskovanje

tega članka predstavi, kako je raziskovalni proces vplival na kontrolno skupino in svojce, ki so sodelovali v programu. Pokaže, kako so udeleženci kontrolne skupine in svojci doživeli krepitev lastne moči in kako so vplivali na razvoj znanja s pomočjo refleksije. Avtorici predstavita tako podobnosti kot razlike v njunih raziskavah in pokažeta, kako nova vednost, ki je rezultat njunega dela, pripomore k razvoju sodelovalnega raziskovanja. Članek skleneva s trditvijo, da vključevanje ljudi z osebnimi izkušnjami v raziskovanje vodi v krepitev moči teh ljudi, razvija nove perspektive v raziskovanju in plemeniti teorijo in prakso socialnega dela.

Introduction

The evidence base for establishing the methodological validity of involving service users in research is increasing in social work and allied health research across Europe (Fox, 2015; Nicholls, 2001; Ramon, 2003; Van Haaster & Koster, 2005; Videmšek, 2009, 2011, 2014; Zaviršek & Videmšek, 2009). Both service users and researchers are seeking to embrace diverse stakeholder perspectives in the research process. Central to this debate are issues of power, how best to involve different perspectives in the development and design of research, and discussion of the validity of the production of knowledge (Fox, 2013; Ramon, 2003; Urek, 2005; Videmšek, 2014; Zaviršek & Videmšek, 2009).

In this article the authors describe two research projects undertaken in Slovenia and the UK, respectively, which involve experts-by-experience and experts-by-caring extensively in their design and development. The first author involved experts-by-experience in her Ph.D. study which investigated the experiences of people with mental ill-health living in group homes in Slovenia. In her doctoral thesis she shows the epistemological shift, produced by the inclusion of people with the lived experience of a mental ill-health crisis and its aftermath, and demonstrated how this can lead to both their individual and the collective empowerment. The second author describes how her own experience of recovery enabled her to explore the usefulness of the recovery model to the lives and caring roles of family members who support people with schizophrenia. We (both authors) initially review how user involvement has developed within these two countries and then consider how our research contributes to this wider field. We address three aspects:

- the interaction between the research process and the co-researchers;
- the influence of service user participation on the outcomes of the research; and
- the influence of service users' and carers' silent knowledge on social work knowledge and practice.

This discussion will enable us to explore the significance of new paradigm research which promotes co-production, adding to the methodological evidence base of involving experts-by-experience in social work research.

Development of user involvement in both Slovenia and the UK

The change in European cultures and delivery of services from total institutions (Goffman, 1961) to care in the community, reflected in both Slovenia and the UK, was accompanied by the development of empowerment philosophies (Ramon, 1991). This reflected the rich flow of notions of user empowerment that accompanied the philosophy of the reintegration of service users into communities, even if reintegration was more rhetoric than reality (Ramon, 1991). In the late 1960s academic researchers began to have an interest in exploring the users' perspective in the research process (Mayer & Timms, 1970); later, a variety of movements led to the inclusion of users in research, from the feminist movement at the end of 1980s, and in parallel to the development of the disability movement (Barnes & Bowl, 2001; Ramon, 2003; Videmšek, 2013). These movements highlighted that

service users' own experiences had been often disregarded and overlooked. At the end of the 1990s, the user movement began to emphasise the importance of user-led research that enabled service users' voices to be heard (Evans & Fisher, 1999; Ramon, 2003; Videmšek, 2009). Thompson (2002) notes that social movements have definitively influenced social work theory and practice in a variety of ways. The development of user-led research promotes a new relationship between the researcher and the subject of the research and moreover between providers of the service and their users.

The service user movement challenged the traditional model of professionalism, emphasising the rights of service users and highlighting their expertise. Numerous changes resulted from the inclusion of service users in research, redefining the relationships of power. As users' voices began to be heard (Oliver, 1992), their perspective began to have a place in the process of research and they were recognised as 'experts-by-experience' (Van Haaster & Koster, 2005). Since 1990, participatory research that emphasises this ethos has emerged, together with action research. Humphries (2001) asserts that those who want to bring about genuine change in the lives of poor and exploited groups need to find new methods and new ways of thinking about social problems. The development of new techniques of data collection and qualitative empirical material analysis provided conditions which enabled the inclusion of users in research as co-researchers. Participatory research involves those who might traditionally have been categorised as subjects of research (Banks & Barnes, 2009; Humphries, 2001), and is based on a partnership ideology.

Service user participation in research is manifested at different levels, with Arnstein's ladder of participation (Arnstein, 1969) being the first presentation of community involvement in research, representing the different levels of involvement that organisations can achieve. INVOLVE, the UK body charged with responsibility for developing public and patient involvement in health and social-care research (Hanley et al., 2000, 2004, 2012), develops this model further and proposes three levels of service users' and carers' involvement in research: consultation, collaboration, and control. Additionally, Staley (2009, p. 13) defines the meaning of public involvement as 'doing research "with" or "by" the public, rather than "to", "about" or "for" the public'.

Approaches in Slovenia and the UK share some commonalities in both co-produced and participatory forms of inquiry. In Slovenia a historical overview shows that participation as such has been part of social work practice from the beginning of professional social work (Vodopivec, 1959). With the development of social work as a science there was an increasing credibility placed on the expert wisdom of service users as they become involved in influencing different levels of research. The major shift towards user participation and user research was driven by both individual disabled activists such as Lamovec (1995) and disability activist groups who impacted the political arena, such as the YHD-Association for the Theory and Culture of Handicap (Pečarič, 2004). Lamovec (1995) published critical articles based on her own personal experiences of mental ill-health and advocated user involvement into research. She wrote a chapter in her book about the epistemological shift in social work practice that accompanies user involvement in research (Lamovec, 1995) and challenged the dominant discourse of power and knowledge production, advocating the credibility of the expert wisdom of service users as they became involved in influencing research. In the mid-1990s people with mental health problems in Slovenia were involved in research (Flaker et al., 1999). In 2001, the very first Roma student who enrolled at the school of social work participated in a national survey on the living conditions of Roma ethnic minorities representing the perspective of the oppressed from the beginning of the research (cf. Minority Protection in Slovenia: National Report. Open Society Institute, EU Accession Monitoring Program, Budapest. CEU Press, Budapest, 2001) (Zaviršek & Videmšek, 2009).

First participatory user-led research with mental health service users was conducted in 2007 (Videmšek, 2009, p. 181); and was built on in 2009 when the same group of mental health service users who contributed to Videmšek's Ph.D. work conducted their own, user-controlled research (Videmšek, 2011). They prepared user-controlled research on the issue of employment, and obtained financial support from the Municipality of Ljubljana (Cigoj, 2009). This was the first example of

research in Slovenia when users with mental health difficulties controlled and conducted their own research. Further examples of user involvement in research, can be found in Slovenia, not only in the field of mental health, but also in the field of intellectual disability (Bratec & Kos, 2011), and cooperative research with older people (Grebenc, 2014, p. 104). Expert user knowledge is now recognised in Slovenia as a valued source of wisdom as service users become leaders in the research process and no longer merely consultants; furthermore Slovenia encompasses all three levels of user involvement with reference to Arnstein's (1969) Ladder of Participation.

In the UK, the strengths approach in social work (Rapp, 1992; Rapp & Goscha, 2012) promoted a new way of working focusing on consumers' strengths rather than their deficits. Currently the personalisation agenda (Department of Health [DH], 2006), underpinning British social care, is a model of practice that seeks to optimise individual users' choice and control of social care resources, building on the notion of user involvement in care. Alongside this, in the UK there is increasing credibility placed on the expert wisdom of service users and carers as they become involved in influencing different levels of research. The involvement of the public is increasingly politically mandated in the development of publicly funded health service research in the UK, due to:

- a commitment to the human rights of people who use services (Uhm, Liabo, Stewart, Rees, & Oliver, 2012);
- its effectiveness in supporting effective methodologies (Faulkner, 2010); and
- reasons of political expediency (DH, 2011).

The requirement for user involvement is reflected in both health (Willis, 2012) and social care (Levin, 2004) practice, and more widely in other disciplines in mental health practice and research (CSIP, RCPsych, and SCIE, 2007; Rose, 2001).

The research studies

The authors present two experiences of involving service users and carers in research in Slovenia and the UK, respectively, which were conducted individually by both authors for their Ph.D.s. Throughout this discussion we consider the contribution of user-led research to the construction of social work knowledge and indirectly on people who use social care services.

The Slovenian study

The research aimed to explore the epistemological shift produced by the inclusion of people with the lived experience of a mental ill-health crisis and observe their empowerment process and outcomes. I (the first author) wanted to ensure that the voice of historically 'silenced subjects' would be heard in order to demonstrate the value of cooperative inquiry (Heron, 1996; Reason, 1994) and its potential impact on the social work profession. I was exploring, firstly, if cooperative research can be a tool for user empowerment; secondly how 'silent knowledge' can influence the research process; and thirdly if I could understand the structure and characteristics of the group home and how the residents, who were involved in the research, might want to change it.

The research process followed nine phases, as described by Flemming and Ward (1999). I used an interpretative methodology adopting cooperative inquiry. Five people with personal experience of mental ill-health were trained as researchers (Videmšek, 2011). Data collection specifically focused on research *with* people rather than research *on* people, (Reason, 1994), a process which prioritises service users' knowledge and experience. Twelve structured interviews, designed and prepared by people with personal experience of mental ill-health were conducted by these same experts-by-experience within three NGOs which supported people with mental ill-health. People with personal experience of mental ill-health participated in all parts of the research and defined the themes, prepared the questionnaire, undertook the interviews, and participated in the data analysis and the dissemination of the results.

The English study

The research in the English experience was undertaken by the second author, a social worker with personal experiences of mental health recovery from schizophrenia. The research aimed to explore the impact of learning about recovery on carers of people with schizophrenia. The recovery approach is a concept and practice that underpins British mental health policy (DH, 2011) and is an aspiration of service delivery. Carers' views and experiences of recovery have hitherto not been investigated (Scottish Recovery Network, 2009), and their involvement in research processes is under-developed (Mental Health Research Network [MHRN], 2012).

A steering group of stakeholders including people from professional, family-caring, and research backgrounds met over a year to develop a training programme on recovery and accompanying evaluation tools to explore the impact of learning about recovery on carers' lives, caring behaviour, and attitudes. I (the second author) as the principal investigator and facilitator of the programme also have my own experiences of mental ill-health which were central to the development of the research and the delivery of the programme. A sample of 11 carers was recruited to participate in a five-session training programme on recovery (delivered by myself and a carer) and subsequent evaluation. Mainly qualitative data was collected with supplementary socio-demographic data. Carers responded to written vignettes at the start and end of the training programme (Hughes & Huby, 2004) with a subsequent focus group to allow them to share and compare their reactions (Morgan, 1998) to learning about recovery, and to evaluate the training programme. The final focus group was facilitated by two members of the steering groups not involved in the programme delivery. Subsequent semi-structured interviews were conducted by me the main researcher with the carers at one month and six months to see if any changes identified following participation in the training programme were sustained.

A Participatory Action Research approach (Freire, 1970) was utilised that acknowledged the my values and identity in the research as the main investigator and enabled the action research cycle to formatively influence the process. The steering group participated in the first action research cycle developing the training programme and data collection tools and the carers were involved in a second cycle that allowed us to develop theory about the meaning of recovery to carers as they participated in analysis and reflection.

Discussion

In order to develop this article both authors, separately and together, identified the themes and concepts that were both common and different to our respective research. We sought to derive explanations for these themes and contribute to the evidence base supporting the development of user-led forms of inquiry. In this section we investigate:

- the interaction between the research process and the co-researchers;
- the influence of service user participation on the outcomes of the research; and
- the influence of service user silent knowledge on social work knowledge and practice.

Firstly we recognise the importance of *interaction between the research process and the co-researchers*. This encompasses both how the researchers' expert knowledge influences the research process, such as opening up new knowledge and ideas, and how the research process impacts on user-researchers, such as building skills and enabling a process of empowerment. During the two years of the research in Slovenia, participants were empowered on both an individual and a collective level. On an individual level, the researchers gained more self esteem and recognised themselves as experts on their particular condition gaining a sense of mastery over their lives. Individually, empowerment was reflected in terms of personal growth, as the following statements from the co-researchers in the reflection meeting show: 'I see myself as somebody who has knowledge.

I started to write stories and look forward to future research. I really like being a researcher' (Sonja, personal notes, 2007). 'The research brought a really positive result of empowerment and, in turn, personal satisfaction. Ever since we have started to work together I have gained some self-respect' (Jože, personal notes, 2007). This appears to be central to attaining a high level of functioning and good outcomes from the illness as they made future plans for their lives. 'Now, when I meet with other, communication is going to other direction. We do not talk only about medication as we did it before, but we are discussing about our future plans' (Milan, personal notes, 2007). They not only made new friends, but constructed a new social network as they developed a sense of social inclusion through completing a valued task. Collectively, people have started to interact and have established their own user-led organisation Mostovi (Bridges) undertaking their own user-controlled research. This tendency to build on experience has also been noted by other researchers (Beresford, 2000; Evans & Fisher, 1999; Videmšek, 2013, 2014).

In the UK research, the carers also went through a process of empowerment. Participation in the training programme enabled the carers to recognise that they needed to become recovery mentors of their relative rather than do everything for the service user. The second author's own experiences as a service user were central to enabling them to understand the service user experience and to understand the impact of their caring behaviours. Although they wanted to support the service user and ensure their comfort and safety, they realised that they needed to become enablers. The carers also began to recognise that they were themselves on a journey of recovery. This journey reflected much of the experiences of recovery that the service users themselves experienced – it reflected the process of moving from chaos and confusion, to involvement of services, recognition of grief, learning to detach with love, and setting a goal of recovery for the carers and the service user (Carers-one-to-one Link (COOL) Recovery, 2003). Carers also began to recognise their own expertise by caring which allowed them to occupy a place of authority in their relationships with professionals.

Related to this discussion, the involvement of service users impacted the *process* of research as both studies completed by the two authors were supported by steering groups which included experts-by-experience and -by-caring. In Slovenia the steering group enabled comparison between questions that were developed by social work researchers and questions that were developed by people with lived experience. It enabled the researchers to review the issues which were emphasised by the different groups. A researcher with such an experience of mental health crisis is not using pre-determined categories, but forms the questions in the most appropriate way to her/his understanding of a phenomenon. In the Slovenian research the user-researchers revealed new themes in their interviews as they allowed service users to address issues outside of the research protocol that would not have been considered by academic researchers; this included: suicide by people with mental health difficulties, a subject often overlooked in group homes, sexuality, forbidden visits and also questions of professional power (controlling the number of cigarettes, restrictions on domestic animals, access to Internet, etc.) (Videmšek, 2017).

In the UK, the steering group participated in the first action research cycle developing the training programme and data collection methods. They contributed to the evaluation of the training programme and commented on the research findings. One carer was involved in the steering group, and also involved in delivering the training programme. Her participation in the research also enabled her to develop skills and build a sense of empowerment. The inclusion of different stakeholder viewpoints allowed greater representation of differing perspectives and values. The second author's own experiences as a service user underpinned the delivery of the training as the carers were able to relate to her own authentic experiences of psychosis and the subsequent recovery journey.

Secondly, in research undertaken by both authors we recognised the different types of knowledge and expertise that contributed to the development of our research findings and how these perspectives influenced the *outcomes* of the research. Beresford (2001, p. 350) argues that:

This changed approach to research and knowledge formation needs to start with the full and equal inclusion of the experiences and knowledges of service users in research. For this to be possible on truly equal terms, requires the full and early involvement of users and their organisations in the construction and process of research and evaluation, as indeed of other areas of social care

Service user and carer expertise-by-experience complemented the practice and academic wisdom of professional researchers.

Central to discussion about the impact of service user involvement on research outcomes is the issue of power and how it is exercised. Research is an expression of power relations, which has a direct bearing on the product of the research or knowledge-building enterprise – the outcome of the research. When service users are involved in research, their perspective becomes one of the most valued qualitative methods for ensuring that their experiences are accounted for. It highlights the centrality of the relationship between the researcher and the subject of research. Questions of power can reflect different interests and levels of analysis that represent very different concerns about power, such as who has power, who can control whom, who can get what, who defines the issue, who decides what to research. These power relations are especially important when users are supported by social workers in carrying out research. Some concerns in the Slovenian context included: issues relating to power relations between the researchers themselves, such as who would determine the research issue? And who would construct the statements and make sense of them? Greater equality in the relationship between the researchers themselves can be enabled through the careful selection of terms used (How do different researchers address one and other?). It is important that the service user researcher is respected and treated as a person with agency and an active contributor to the research, not a passive object that is just one part of the research process.

In the UK, some concerns were expressed about using the terminology ‘carers’, ‘family members’ or ‘relatives’. This was quite controversial as not many of the carers in the programme recognised themselves as such, and identified themselves as ‘mum’, ‘dad’, or ‘sibling’. Indeed the word ‘family member’ can be quite limiting as not all carers have a kin relationship (MHRN, 2012). This terminology can be both simultaneously empowering and disempowering. It can give family carers an identity which allows them to acknowledge their caring role or it can make them feel negatively labelled and stereotyped, and force the service user to recognise themselves as in need of a carer (Kilyon & Smith, 2009). Despite underlining the value of service user involvement, it can still be difficult for service users and carers to believe they have power in a research process because their contact with services can lead them to feel under-skilled, under-prepared, and often disempowered (Fox, 2009).

Finally, this research shows the potential for silent knowledge which is derived from expertise-by-experience to influence social work knowledge and practice. Silent knowledge can be defined as knowledge that each person with experience has; silent knowledge, as stated by Urek (2005), is enabling those without social power to express their own perspectives. In the Slovenian research, different sorts of knowledge helped the team of co-researchers to understand the complexity of social work practice as the experts-by-experience co-produced new knowledge from their own lived experiences of using services. From the data, it emerged how important relationships in the group homes are (especially the relationship between them and social workers) and how they value a way of working based on partnership and respect and that values their life experiences (‘I am not sure if social workers see me somewhere else than here’); furthermore they reflected on the importance of time and its meaning in their life as they considered how long people should stay in group homes and the positive and negative aspects of living there, either temporarily or for longer periods. Through the research process, both the first author and the co-researchers were able to identify knowledge that emanated from the perspectives of experts-by-experience using social care (Videmšek, 2014, 2017).

In the UK, the wider carers’ group influenced the second action research cycle of the research project developing the content, format and process of the training programme and the development

of theory about carers and recovery. The carers' participation in the research was situated at the level of 'contribution' as described by Sweeney and Morgan (2009). Sweeney and Morgan (2009) propose an extra level of involvement between consultation and collaboration on the INVOLVE level which they call 'contribution' and define as: '... research where service users/survivors make a significant and meaningful contribution to research but with power and decision-making still residing with traditional researchers' (p. 9). This demonstrates the contribution of the silent knowledge to the UK study and how it influenced the development of new theory about the role of carers in recovery. (This is further discussed in Fox, Ramon, & Morant, 2015.)

Both the two main authors and the co-researchers in the studies found that when the needs and views of users are reflected in research, it is more likely to produce results that can be used to improve social work practice and articulate the answer to HOW to do it differently. The Slovenian research shows that when experts-by-experienced are involved in research this can lead to the creation of services tailored to the individual. Experts by experience suggested, 'In the house it should be written that domestic animals are allowed and that the owner takes care of it.' 'Each of us decided by ourselves the amount of cigarettes. If we need help we will ask for it.' 'Risk is permitted.' The UK research led to the development of a service model based on the carers' experiences of supporting their family member by using the recovery approach (Fox et al., 2016). This research generated a triangular model based on the UK Triangle of Care (Worthington & Rooney, 2009) that represented how service users, carers, and professionals could work together to support both the service user's and the carer's recovery.

Furthermore both experiences confirm the findings of earlier studies (Evans & Fisher, 1999; Home, 1999; Ramon, 2003; Schafer, 2003) that cooperative and participatory inquiry contribute to the empowerment of individuals as they are able to develop their expertise which is valued in research processes. Both experiences show that inclusion of people with personal experience of mental ill-health and their carers into research can validate the so-called 'silent knowledge'. The research findings lead both authors to suggest that the inclusion of people with personal experiences enables more precise knowledge about the life of people with the lived experience of mental health crisis and their carers, and that experience is a valid source of knowledge.

In summary, user-led research is important for a number of reasons:

- (1) Co-production contributes to the language of change. If we hear the words of service users and learn from them, this can lead to the production of new knowledge.
- (2) The process of reflexivity undertaken in partnership with our co-researchers led to the development of new knowledge.
- (3) Respectful alliances with experts-by-experience enable researchers to see the situation from different perspectives.
- (4) Co-production is based on a strengths perspective, which acknowledges that service users are active and visible participants. This acknowledgement subsequently influences social work practice more widely.

Conclusion: the contribution that experts-by-experience can make to knowledge construction

One of the major impediments for service user involvement in research is a strong professional limitation that regards service users as being needy and dependant, lacking competency and skills (Schultz, 2007; Zaviršek & Videmšek, 2009). Inclusion of people with lived experience in research validates notions that service users have their own, original, experiential knowledge, or, as defined by Haaster and Koster (2007), knowledge from 'the bottom' based on personal experience. It is, therefore, imperative to enable user experiences to influence the creation of social work theories and practice. The role of a professional worker is to acknowledge such knowledge, as Ramon (2003, p. 16)

states: 'user research has been developed as a method of creating new knowledge, hitherto hidden and often described as invalid by professionals'. Ramon (2003) argues that knowledge gives power, and is often used by those in power for their own purposes; indeed knowledge has the power to construct the truth, meanings, and contribute to solutions.

The involvement of service users in research can begin to transform social work theory and practice. A number of international studies (Beresford & Croft, 1993; Maglajić, 2007; Ramon, 2003; Schafer, 2003) as well in Slovenia (Grebenc, 2014; Grebenc & Šabič, 2013; Lamovec, 1995; Urek, 2005; Videmšek, 2009, 2011, 2013; Zaviršek & Videmšek, 2009) and the UK (Fox, 2015; Slade et al., 2010) confirm that the involvement of people with lived experience in research challenges traditional notions about the construction of knowledge in social work practice and theory. The methodological approaches in both research studies reflect the principles of social inclusion and the post-modern concepts of social work which are identified in co-creation, the ethics of participation and the exploration of the different perspectives of power. Without the methodological developments in this new paradigm research, the founding principles of social work (ethics of participation, empowerment, participation, co-creation of solutions) would exist at the level of abstract rhetoric rather than real social work practice. In conclusion, we would argue that it is unethical to speak about social inclusion unless those who are the subject of the discourse can effectively participate – otherwise this would only further compound their discrimination and social exclusion (Videmšek, 2011).

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Dr Joanna Fox is a Senior Lecturer in Social Work at Anglia Ruskin University. I have my own experiences of recovery from mental ill-health as a service user and a commitment to involving people who have used services and their carers in social work education and research. Current interests are in the development of recovery education training programmes for carers of people with mental ill-health, specifically focusing on blended learning approaches.

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