Expert by experience research as grounding for social work education

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Routledge
Taylor & Francis Group

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ABSTRACT

This article is based on an investigation that involves five experts by experience in the field of mental health and eight students of social work. Both groups investigated the experiences of people with mental ill-health living in group homes. The article identifies the advantages if the researchers are expert by experience and the epistemological shift produced by the inclusion of people with the lived experience. Expert by experience research is a challenge to both experts by experience and for social work practice since it promotes the basic principle of social work as the science of doing. This study was based on the assertion that the real integration of theory and practice will not come from a rigid body of knowledge, but from the humility to learn from experts by experience.

Involving experts by experience into research

In the last two decades, we have witnessed a strong tradition of involving people with personal experience as active members of research teams (Beresford, 2000; Faulkner, 2009; McLaughlin, 2009; Ramon, 2003; Rose, 2009; Videmšek, 2009). An important source for the involvement of experts by experience into research was the rise of social movements like the feminist and peace movements and especially those led by service users and carers, particularly in the field of mental health, psychical and intellectual disabilities (Oliver, 1992; Rose, 2001; Videmšek, 2011, 2014; Winter & Munn-Giddings, 2001; Zaviršek & Videmšek, 2009). According to Thompson (2002) social movements played an important role in ensuring that service user's views were taken into account as relevant in the policy, practice development and implementation, as well as the evaluation of services.

Involvement in research is first recorded in the late 1960s when Mayer and Timms (1970) drew attention to service user perspectives; *The client speaks: working class impressions of casework*. The study was conducted in 1968 in London and included the perspectives of those who were satisfied and dissatisfied with the social services they received. Their research aim was to find the reasons which had led to the users' satisfaction or dissatisfaction with the service, and to present through a user perspective the ways users establish connections with existing services. In Slovenia the major shift towards expert by experience involvement was

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the result of disability activists who started to publish critical books, articles and daily news reports based on their own personal experiences with mental health services and with social workers. One of the first critical books on mental health was published by a professor and long term mental health survivor Tanja Lamovec in 1995 (Zaviršek & Videmšek, 2009). She also wrote about the phenomenological approach in research and the need for the involvement of experts by experience in research (Lamovec, 1995). She and others had pioneered a politically aware, user led organisation that had not only set up the first advocacy service along with a number of non-governmental organisations (NGO's) for and with people with mental health problems in Ljubljana, but also challenged the way knowledge was produced.

Not only social movements and activists, but also the development of new techniques of data collection and qualitative empirical material analysis provided conditions which enabled the inclusion of experts by experience into research as a researcher. Mesec (1998) states that in the past 40 years social work has witnessed a true renaissance of the so-called qualitative methods that used to accompany social work's first steps as a science (Mesec, 1998, p. 19). The review of these methods shows that changes in research in individual time periods were mainly due to researchers seeking to gain a better understanding of changes in society and to better represent the characteristics of people's actual problems.

Expert by experience involvement in research is an innovative topic. As Reason (1994) suggests, research should be done 'with' people, and not 'on' people—three levels of expert by experience involvement in research can be summarised as:

- Research within which users are members of the research team and are in the position of consultants—*consultation* (Barnes, 1993; McLaughlin, 2006, 2009);
- Research where users carry out research with the support of professionals—*collaboration* (Beresford, 2000, 2001; Humphries, 2001; Ramon, 2000);
- Research that is *user-controlled* and led (Ajduković, 2008; Beresford & Rose, 2009; Evans & Fisher, 1999; Videmšek, 2009; Wiltshire & Swindon Users Network, 1996).

All those levels speak about different points of involvement of service users. Consultation may be the first point of involvement but does not guarantee that any ideas, changes or issues raised by those who are being consulted will have any impact or influence whatsoever on outcomes (McLaughlin, 2009, p. 27). Collaboration implies that service users will be listened to and their ideas will have an impact upon research. Service user controlled research presents a challenge to traditional ways of research production. The history of service users involvement is defined with classifications and typologies started with Sherry Arnstein's (Arnstein, 1969) 'ladder of participation'. Arnstein (1969) defines eight levels of citizen participation. The eight types are arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the end product. This involvement ranges from non-participation to citizen power (Arnstein, 1969). The bottom rungs of the ladder are one Manipulation and two Therapy. These two rungs describe levels of 'non-participation'. Rungs 3 and 4 progress to levels of 'tokenism' that allow the 'have-nots' to hear and to have a voice: three Informing and four Consultation. When participation is restricted to these levels, there is no follow-through, no 'muscle', hence no assurance of changing the status quo. Rung 5, Placation, is simply a higher level tokenism. Further up the ladder are levels of citizen power with increasing degrees of decision-making influence. Rung 6, Partnership, enables them to negotiate and engage in trade-offs with traditional power holders. At the

topmost rungs, 7 Delegated Power and 8 Citizen Control, citizens have become the major decision-maker and assumed full control. (Arnstein, 1969, p. 217–218).

McLaughlin (2015) defines four different models of service user involvement. These models move from viewing service users as objects to subjects, to social actors, to active participants (McLaughlin, 2015, p. 155). The main distinguishing feature of these models is the question of the degree of power. The above implies that inclusion of experts by experience in research represents a fundamental shift in power relations. Traditionally, an expert by experience in research was restricted to being the object of research. One of the biggest challenges was how to change this position. A review of the literature shows that service user's involvement in research represents a shift in power (Beresford, 2000; Beresford & Rose, 2009; McLaughlin, 2009; Powell, 2009), presents practical examples of service user's involvement (Beresford & Rose, 2009), introduced knowledge production (Lamovec, 1995, Powel, 2009, Beresford & Rose 2009), principles and concepts about service user research (Beresford, 2000; Faulkner, 2009). A number of different approaches can be recognised, such as consumerist approach, democratic approach. The first approach generally starts with policy and service system, the second is rooted to people's lives and their aspirations to improve the nature and conditions of their lives (Beresford, 2000; McLaughlin, 2009). Reading the published literature suggests how you can do the research and present principles and priorities of service user research. Literature review leads us to make practical use of the research and all this awareness. We wanted to add knowledge production and present whether there was a difference between the knowledge claims of research that is done by service users and the research that did not include service users.

With this research, I wanted to explore the knowledge production. I wanted to show, as noted by Jackie Powell (2009), that real integration of theory and practice will not come about through a ponderous, rigid body of knowledge, but from the humility to learn from practitioner's experiences (Powell, 2009, p. 325).

Methodology

In involving experts by experience[1] I sought to challenge traditional research and value the experience and knowledge of experts by experience.[2] I sought to find out if the involvement of experts by experience would lead to any changes in the context of research. For this study I undertook research with two groups of researchers, experts by experience and students of social work. Five experts by experience with whom I had cooperated previously on European mental health projects agreed to take part in the research along with 3rd year social work students.

Those two research teams were an educational experiment in which I wanted the student to understand better the nature of user led research, and to explore whether there were differences between the student's and expert by experience's research design. The study also wanted the student to reflect on what they had learned of the advantages and disadvantages of involving experts by experience in research. The main question was not just a question of 'what is different when the researchers are expert by experience?' but 'what can we learn from this process and how do we all, as researchers (student or expert by experience), shape knowledge production?' Efforts have been made to measure the extent to which researchers with different backgrounds conduct the investigations differently. I try to answer two research questions in this process:

- Can we perceive differences between experts by experience research and a trained researcher (trained student)?
- How can an expert by experience's perspective be identified through involvement in research?

Both groups of researchers had the same purpose: exploring group homes in Slovenia. The topic was chosen by experts by experience. The students also agreed to explore group homes for people with mental health difficulties in Slovenia. A sample of 20 interviews were undertaken, with 12 completed by experts by experience and 8 by students, covering a total of 5 different group homes. The research process followed two phases of research. The expert by experience researchers were involved in articulating the major issues they would like to explore. They chose to explore group homes in the field of mental ill health since three of them live in group homes.

We used qualitative methodology. The data collection technique used was semi- structured interviews that offered insight into individual experience, enabling us to explore user's narratives of experience and view of living in group homes. The semi structured interview were structured into four segments: (a) control; (b); social capital (c) choices (d) future perspective and used both open and closed questions.

In the second phase, the student researchers were asked to prepare a questionnaire on the same topic that had been previously chosen by the experts by experience. They were asked to define the research questions and to prepare the questions for the interview. They prepared their own questionnaire and chose the group homes where they undertook the data analysis. The students were also asked to record their critical reflections on their experience.

For exploring the main ideas and phenomena of expert by experience research, I used conceptual frameworks (Miles & Huberman, 1994). Conceptual frameworks help us to form a tentative theory of the phenomenon that we investigate (what is needed if the researchers are expert by experience, what is going on (in the existing services), what we have been able to see in two different research teams).

The analysis process followed a series of steps. Each researcher read all the interview transcripts and recorded their findings (perceptions, key statements and findings). In the group meeting we discussed the findings and related these to the literature review. We focused on the analysis of the qualitative interviews data in order to explore the differences between the two research groups. For both groups of interviews we added preliminary codes. Than we put those codes into a set of themes. After that we compared the themes, discussed them and compared the results, identifying similarities and differences.

Because the aim of the research was education, I used concept map tools. Concept maps are based on Ausubel's (1968) theory of meaningful learning. According to his theory, meaningful learning is based on a constructivist epistemology, which posits that human learning is based on cultural, religious and contextual situations and conceptualisations (Ausubel, 1968). Concept mapping, as developed by Novak and Gowin (1984), is unique because it makes concepts, and propositions composed of concepts, the central elements in the structure of knowledge and construction of meaning. The concept maps method helps us to understand and pictorially represent our thought patterns in an organised and structural process (Novak & Gowin, 1984) and I used grounded theory (Glaser & Strauss, 1967) to inductively develop key themes during the research process.

For the research proposed we did not need ethical approval or any ethical research governance since in Slovenia, we need ethical approval only if the research is done in an institution like a psychiatric hospital. Before we started the research we asked managers of the group homes for their agreement. We outline basic information about the research and its purpose and the right for participants to not participate whilst advising the staff we would be contacting them. We did consider all the potential risks to participants, and have procedures for how to continue with the work and for maintaining confidentiality. We have been aware that ethical issues are important in the research, especially if service users as researchers are involved. Before we started to do the research, we considered the need for support of service user researchers, respect for autonomy, anonymity and confidentiality, storing of data (all collected interviews have been stored at the Faculty in a the locked drawer whilst electronic data files have been password protected), rewards and recognition (two of service users choose to participate in an international conference and have been supported to do so, all others attended a local social work conference).

In the following text, I outline some of the key findings and examine what needs to be in place to promote and ensure experts by experience involvement.

What we can learn from our experiences?

The main purpose of the research was to show the knowledge production and differences between two different groups of researchers. From our experience we can outline some major differences that support involvement of experts by experience in research. Our findings 'demystify research' as a strictly professional form as said by Shula Ramon (2003) and contributes, as Maglajlić (2007) points out, to the 'development of theory, values and practice in a way which is not based on the premise that all theories are formed by dominant groups of people (Maglajlić, 2007, p. 57).

Based on the research, we can list some advantages for involvement of experts by experience in research:

(1) Experts by experience clearly define the problem because they understand the situation. They know what it feels like to undergo treatments and their various side effects, how it is to use the social services and be with those who you do not know or want to be with. Because of the aforementioned reasons, they have a good idea about what research questions should be asked and how questions might be asked differently. Beresford and Rose (2009) defines this as the uniqueness of experts by experience. In our experience students needed more time to identify the research problem and key research questions whilst experts by experience could identify these straight away.

(2) Questions are grounded in their life situation. Questions are simple, concrete and direct. In our situation that means that expert by experience researchers posed more direct questions than the students. For example, the experts by experience posed such questions as: Do you want to have a domestic animal in your group home? Do you like that the social worker is giving you the amount of cigarettes you can smoke? Do you want to have the bell on your door? Students however asked: How did you come to be in a group home? Do you have your own room?

Expert by experience research has proven that experts by experience pose different questions than those raised by other experts without experience, namely they are linked to concrete life situations, reflect knowledge of living conditions in the group and focus on specific changes which could be brought about through the research. As stated by Ramon (2003), users participating in user research apply their emphatic understanding as a research instrument with which to pinpoint the impact of important research questions vs. the less important ones (Ramon, 2003, p. 5). To affirm that experts by experience pose the right questions because they know the situation opens the issue of who can be called a service user researcher, as asked by McLaughlin (2009). He raises this question for further debate and consideration. In our experience we can assert that because experts by experience are recipients of the service, they add more to the process than those who are not, as it concerns then and is important to their life situation. One of the expert by experience interviewers said: 'Finally I haven't been asked the same questions as usually'. Experts by experience are able to see the policies and services both from the perspective of being a recipient of the policies and services but also from the point of view of what is required to make a difference in their life, as pointed out by McLaughlin (2009, p. 81).

(3)   New topics are identified. Investigation shows that experts by experience open up new topics and give us evidence for new knowledge. McLaughlin (2009, p. 33) said that experts by experience are able to prioritise topic areas and this a recognition that their experience provides them with significant insights into the topics under consideration. In this research 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.).

(4)   The nature of the responses to interviews by experts by experience were different than those from student interviewers. The answers were more direct, personal, honest and open compared to those obtained by student researchers. Several researchers and service users report that (Beresford & Rose, 2009; Faulkner, 2009; Ramon, 2000; Rose, 2001). This can be explained by the fact that many people will only allow themselves to reveal their vulnerability, and allow others to approach them, in contact with a peer (Lamovec, 1995). The second reason unavoidably lies in the interviewee's relationship of dependence on the service (in our case the group home unit), and that is why respondents have difficulty revealing their true opinion of the service, while, when speaking to individuals with a similar experience, they can be more open in revealing their own experience. When service users feature as researchers, they are recognised by the respondents as equal interlocutors with whom they can speak more openly (without censorship). Power relations at the level of the relationship between the researchers and the object of the research are manifested in different ways. Researchers reveal their power by acting as specialists in their field, enjoying a reputation and having the possibility to ask questions, while the researched often have no power. In terms of power relations, it is all the more important that researchers be people with similar experience as those they are researching.

(5) If the needs and views of users are reflected in research, it is more likely to pro-
duce results that can be used to improve social work practice and articulate the
answer to HOW to do it differently. In our case, 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 themselves about the amount of
cigarettes. If we need help we will ask for it'. 'Risk is permitted'. I claim that expert
by experience research represents the basis for the creation of services tailored to
the individual. By entering the research field experts by experience are put in the
position of co-creators of theory which is important for 'actionable knowledge'.
Actionable knowledge in social work is knowledge that is shared with people,
we jointly use it in a working relationship. (Čačinovič Vogrinčič, 2002, 2015).
Experts by experience thus become part of looking for answers and co-creating
solutions. From being passive service receivers, they obtain the position of active
solution searchers.

The inclusion of experts by experience in research brings several advantages, not
only in obtaining better results but also because expert by experience involve-
ment in research can be used as a tool that actually brings empowerment to the
expert by experience. In this research work, this occurred both on the individual
and collective level. Experts by experience researchers have since continued with
their own research.

(6) An important issue is in the creation of new knowledge. Humphries (2001). sug-
gests that there is a need for research to generate different sorts of knowledge for
understanding the complexity of social work practice. Humphries (2009) writes
that participatory approaches open the space and recognise the knowledge of
marginalised groups and the subjective elements of human experience, that is,
the meanings attributed to events and behaviour by particular social actors.
(Humphries, 2009, p. 313). Ramon (2003) pointed out that 'knowledge itself is
powerful in providing a way to make sense, give meaning and predict reality … it
provides a new way of looking at what has been taken for granted' (Ramon, 2003,
p. 16). Knowledge as such is not monopolised and reserved for professionals but
was shared and distributed to the participants in the research. Participation of the
service users ensures reconstruction of knowledge and helps to develop more a
'democratic social science' as Oakley stated (1998, p. 725). Rose (2009) said that
there is no 'universal knowledge produced' but only particular knowledge pro-
duction through different standpoints. Different standpoints produce 'different
truths' (Rose, 2009, p. 41).

This research shows that different sorts of knowledge helps us in understanding
the complexity of social work practice. In our investigation new knowledge pro-
duction lies in new themes that have been opened by experts by experience and
also in the explanations of the existing services. From their questions and answers,
we have been able to learn how important relationships in the group homes are
for them (especially the relationship between them and social workers). The main
model of working with them will be a partnership that is based on respect and
that values life experiences. ('I am not sure if social workers see me somewhere
else than here'). They raised the importance of time (how long people should stay
in the group homes. What are the positive and negative sides of limitations on

Principles and *values* of professional social work. We want to follow the principle of users' control over the whole process.

Philosophy that is based on human rights and an awareness that there is more than one way to produce knowledge and more than one truth.

Orientation, that leads social workers towards radical social work. Radical social work is not only about helping the individual to fit into the system, but also changing the system to fit the individual.

Moral courage, to implement what we see and hear in the field work. With that, we enable that theories are not coming only from professional deduction but from the experience of experts by experience

Obligation to be beyond existing practice and change it.

Moral vision requires that we not only act within existing frames of understanding, but that we are able to see what should change or happen in response to our moral stance or professional values.

A *process*, whereby we engage with experts by experience in respectful dialogue.

staying in the group homes etc.). Through our research experience, we are able to identify knowledge of what is an expert by experience perspective in social work. We can offer a deeper understanding of user perspectives to those who will always be without this component. User perspective in social work practice is:

(7) Experts by experience understand the system and have contact with other service users. In a way we can say that an expert by experience has easier access to data and interviewees. McLaughlin (2009) mentioned that people with mental ill health (and other stigmatised groups as well) are hard to reach groups. Experts by experience are more likely to know where others in similar circumstances or conditions congregate, thus providing greater access to the target population (McLaughlin, 2009, p. 33). From our experience, it was quite clear that interviewees would rather talk with someone with the same experience. If the researchers are expert by experience there is a more equal relationship. Lamovec (1995) pointed out that because an expert by experience has the same experience, people are more ready to talk with them without fear of what will happen afterwards. Easy access can also be explained by the fact that experts by experience know each other. Access to respondents is direct and not chosen by other people. (Students need to ask social workers to help them find some respondents).

Inclusion of experts by experience in research ensures that theories are also generated from experts by experiences and not only from professionally conceived deductions (Powell, 2009; Videmšek, 2009). As I have shown so far, by including people with lived experience in the research, we treated the expert by experience perspective as the starting point for our understanding of the work. We should also remember that some preconditions need to be obtained before involving experts by experience in research. I identified some preconditions that need to be settled before we do the research. Otherwise, we can face the danger that involving service users in research becomes merely propaganda and thereby undermines contributions to results.

Preconditions for involvement of experts by experience in research

Involvement of experts by experience in research connects with social work concepts such as empowerment, normalisation/social role valorisation, and also resonates with social work values: rights of equal citizenship and self advocacy. To enrich these values we need to address key questions.

Why do we want experts by experience involved in research?

Ostrer and Morris (2009) point out that it is more likely for academics to approach service users to take part in their research than vice versa. Researchers need to be aware that involving service users in their research will require them to be reflective and creative (Ostrer & Morris, 2009, p. 80). The first question to be resolved before any contact with experts by experience is to consider precisely why we want their involvement: is it merely to satisfy the requirements, or because it is in fashion, or is it because there is a considered and genuine belief in the value of user involvement? McLaughlin (2009) pointed out that it is quite clear that involving service users is justified in terms of making traditional knowledge claims (McLaughlin, 2009, p. 79). The reason for involvement should also lie in willingness to implement the main concepts of social work, such as: empowerment, co-creation, the ethic of inclusion etc.

In our case, I was clear that introducing an expert by experience perspective could positively influence the content of their research and make it more relevant to social work practice. I wanted to show that theory can be put into practice and that the involvement of experts by experience can be a tool for empowerment.

How will experts by experience be involved in the research process?

Experts by experience involvement in research may occur at many different levels as we have shown so far (Arnstein, 1969, Beresford & Rose, 2009; McLaughlin, 2009). In our case, experts by experience have been involved as researchers with full control over the process of research (from defining the topic, creating the questionnaire, undertaking the interviews, analysing the data and disseminating the findings).

How do we recruit experts by experience to become researchers?

One of the most productive ways of approaching experts by experience is through relationships that have already been established locally (e.g. with NGO's, with user groups). We can also invite them through less direct approaches (e.g. through posters or advertising in magazines, newsletters and papers). This approach may also be useful and might possibly recruit a wider range of users. In our case, the team knew each other, since we had cooperated on the European project Experience Involvement (EX-IN). When the project was finished some experts by experience expressed the wish for further cooperation. One member of the team also recruited new members through a presentation to NGO's.

I also asked experts by experience why they wanted to be involved. The answers obtained by our experts by experience researchers pointed to a combination of reasons, related to their

mental ill health situation in combination with social services, as well as personal reasons (to be part of something new, to be away from the services) and also help to generate change.

What proposal should be prepared for presentation to experts by experience that want to join?

We need to explain why we would like to involve experts by experience in research. Once the decision to involve them has been made, a clear outline of the process and cooperation including training programme should be prepared and presented to experts by experience.

A genuine dialogue and trust needs to be developed if we want to capture the diversity of knowledge as a source of richness in understanding the perspective of life experience of service users, leading to a new formulation of 'social problems'.

However, the main problem that emerged was their lack of confidence in the research process. I have therefore set up a training programme with the aim of helping to increase confidence through training programmes. We also need to know that training programmes are not enough. We need to ensure that users are supported during the whole research process.

Training programme

Ramon (2003) stated, the research cannot be of high quality, if the researchers are insufficiently prepared to carry it out. Researchers need to be aware that 'professional researchers' are usually employed to do the research. They are skilled in their work. With this in mind, I prepared and developed the training programme for experts by experience; it was supported and led by me and one of the experts by experience. The training was divided into three parts. The first part of the training programme was an introduction (who we are; why they would like to do the research; our expectations. The second part included information about the research and a clarification of the purpose of the research, as well as a discussion on roles, responsibilities and ethical issues. The third part of the education programme addressed how field work is to be conducted, including actual examples (how to initiate an interview; self-presentation; handling difficult situations; listening; writing up). A lot of the time was devoted to self-presentation, to questions about handling difficult situations and to listening skills, writing up and dealing with one's own emotions. (Videmšek, 2009, p. 182).

Setting up research design

Who decided what the research is going to be is a key question of power and is also a question of funding. McLaughlin (2009) pointed out that involving service users in research is often written as if there were no costs and this is patently not the case. He said that involving service users in research is not a cost neutral situation and both those who are championing this approach, and those seeking to use it, need to first consider the implication of their choices, both in terms of benefits and costs (McLaughlin, 2009, p. 35). Our research was not financed and was done for educational purposes. During the research, I was able to cover the experts by experience travel costs and offer them some refreshment during the meetings. Beresford and Rose (2009) pointed out that one of the sharpest expressions of

the inequalities of power affecting service users research is their unequal access to finding support (Beresford & Rose, 2009, p. 19).

It is not useful, however, that the academic researcher set out a precise proposal especially if we want to have joint research with a lot of apparent scope for expert by experience involvement. Our study came about directly as a result of expert by experience in the field of mental health interest about living in the group home. The topic was obviously relevant to them. The training programme helped every one of us to be involved in discussing the research design.

Doing the research and support during the interviewing

If we want experts by experience doing the research, we need to ensure supervision during the research process. Several reports have noted that practical, emotional and research support are critical ingredients of success (Delman & Lincoln, 2005; Faulkner, 2009; McLaughlin, 2009). McLaughlin (2009) suggested that during the research the lead researcher should also be sensitive to the needs of both service users co-researcher's and respondent's discomfort. (McLaughlin, 2009, p. 58). I ensured that we have regular group supervision and have been available for individual supervision when someone needs it during the research process.

Analysis

Experts by experience should also be involved in analysis. Although the type of data analysis may be fixed, the interpretations of data may vary considerably depending on who is doing the interpreting, since tables of data rarely come with their own explanations and no interpretation is value-free.

Working with different interpretations of the same data may provide new evidence and exciting lines of investigation, which had not been obvious at the beginning of the study.

Writing up the results, papers

If we want to ensure, that experts by experience have control over the whole process of the research, they should be supported also for writing up the results. In our investigation, we spent quite a lot of time on this discussion. We debated as to whether the expert by experience researcher wished to write the report and who would take the lead on that. Eventually, it was agreed that one expert by experience will start the write up and the rest of us will help. Not all of the research team wanted to participate at that stage. However, it was agreed in the group that all the names of researchers would be written on the report.

Dissemination

Research results are often disseminated in lengthy documents. Delmar and Lincoln (2005) demonstrated that research findings are more likely to have a policy impact if written up as brief summaries and without jargon and/or delivered orally. The involvement of experts by experience in dissemination is essential so that information is presented in an easily accessible and relevant form and any queries are addressed in an appropriate way. Research 'subjects' are often the last people to know the results of investigations in which they have

participated, and are frequently left feeling used and unclear about how the research they have participated in will influence the practice.

The dissemination of research findings generally occurs in journals and during academic conference presentations. These usually have an impact only on a relatively small number of readers who are research-oriented. Dissemination occurred on a number of occasions. One member of the expert by experience research group attended several Gamian-Europe conferences. Experts by experience who have participated in research design, data collection and analysis, were in an excellent position to explain the research findings in a clear and thoughtful way. The most important dissemination for experts by experience was delivered at the Congress of Social Work in Slovenia.

Sustainability

Sustainability is demanding because such an involvement requires a continuation of the participatory process. In our case, experts by experience continued to be involved in research. Experts designed their own user led research. They managed to obtain funding for their own research from Ljubljana Municipality (2009). In user led research, they explored employment conditions for people with mental health difficulties. In 2010 the same group led their own research on living conditions for people with mental health difficulties (Videmšek, 2014).

Although I outline many advantages that are claimed for user involvement in research, their involvement is not without pitfalls.

Barriers to expert by experience involvement in research

Involvement of experts by experience in research also has some limitations or pitfalls. Rose (2009) pointed out that some criticisms revolve around the idea that user research is subjective, anecdotal and carried out by people over-involved in what they are doing. Such criticism is a counter-point to how mainstream researchers conceive what they are doing. That is, that their research is objective, produces ontological truths and that the position of science is neutral. Beresford and Boxall (2015) added that expert by experience research is still not seen as passing the test of positivist research.

Another criticisms lies in losing the objectivity of the research and its critical distance. People with experience are likely to have been or remain involved in practice and bring a greater awareness of the 'angry words' or feeling, but the question is how objective are they? How objective can people with experience that are living in the same circumstance be? Are they concerned with their interest or are they interested in social change? Participatory user led research seems to be too partisan and lacking objectivity and can be criticised as utopian, as relying on rational consensus and as being naive about group processes.

Barriers can also be dual relationship. In experts by experience research, we should think of the concept of dual relationship. We can understand double relationships as interconnection between different roles that people play (leader of self-help group, resident of group home, past resident of institution, etc.). A danger in this kind of relationship is in the risk of exploitation of the position. It is clearly known that experts by experience are very vulnerable and may have faced many traumas that happened to them over their lifecourse. We cannot assume that if someone is expert by experience in the field of mental health,

they will necessarily be a good researcher. We need to be mindful of whether an expert by experience will necessarily be a good researcher.

Another potential drawback of participatory user research is its preoccupation for equalising of power between professional researchers and user researchers. The question is how we can ensure equality if inequality exists in the research (payment could be one of the unequal parameters), but this is the debate that is relevant for all research approaches that strive for participation of marginalised groups and needs to be discussed further.

Conclusion

The aim of this article was to present how students of social work can learn from the first hand experiences about different types of research and recognise how experts by experience knowledge can be a valued contribution to changing existing social services (Beresford & Rose, 2009; McLaughlin, 2009; Powell, 2009; Ramon, 2003). Going back to the beginning of the article, we were asked to consider whether we can perceive differences between experts by experience research and a trained researcher (trained student). The article leads towards the answer that yes, we can see the differences in involving service users in research and the experiment identified above has implications for social work education. Students recognised the value of experts by experience research and the place of first-hand experience as a source of knowledge. As Beresford (2009) notes, such experimental knowledge is seen as having key importance in survivor research (Beresford, 2009, p. 13). Students learned the importance of the experts by experience standpoint, that those who have been recipients of services have a different standpoint and produce 'different truths' as noted by Rose (2009, p. 41). From this experience, it can be shown that students can recognise the power imbalance between different researchers - experts by experience and academic researchers. This can be acknowledged through the different statuses that researchers have (paid/unpaid, high/low status in society). The students learned that experts by experience research is challenging and also valuable, not only for researchers but for the social services in general. They have learned that seeing experts by experience as only deficits or 'with problems' is a major cultural obstacle, which prevents the development of service users' involvement in research (Ramon, 2003). In the article I have highlighted some of the reasons why experts by experiences are getting involved in research.

Methodologically, without the inclusion of experts by experience, post-modern concepts of social work which are reflected in solution co-creation, the ethics of participation and power perspective, would be only abstract theories about social work rather than theories for social work. Experts by experience research contributes to the development of theory, values and practice that is based on the assertion that the integration of theory and practice will come from the contribution of both experts by experience alongside professionals knowledge (Powell, 2009).

Notes

1. An expert by experience is someone with experience of using social services now or in the past (read more about this in Haaster & Koster, 2007; McLaughlin, 2009). In our case experts by experience have been people who use services and who have done so in the past. I am very aware that an expert by experience can have a double identity (being a student and service user, or, academic and service user).

2. Expert by experience knowledge is in the literature also described as experimental or direct knowledge, as lived experience and as from experts by experience. The key point lies in the fact that people are experienced and it is learned from personal experience. This is not to deny the existence or validity of professionals' knowledge or the fact that they are based on direct experience. It means first-hand experience and reflection.

Disclosure statement

No potential conflict of interest was reported by the author.

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