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CRITICAL ISSUES IN THE DEVELOPMENT OF SERVICE USER INVOLVEMENT

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Introduction

Service user involvement continues to grow as an integral part of policy and practice in regard to many aspects of health and social care, professional education and research. This is particularly evident in the UK from where we as authors write, but more importantly, it has become an international development, and there are important examples of service user involvement in many other countries, to which this chapter will also refer. While much progress has been made with regard to service user involvement, it is also important to critically reflect on those key issues which have the force to encourage yet impede its development. Understanding the history of ‘involvement’; its key ideological and policy influences; debates on knowledge and theory; and issues around tokenism, power, social exclusion and othering are aspects of the undergirding conceptual building blocks which are necessary to interrogate in the process of understanding why service user involvement is necessary in the overall architecture of human services policy and practice. This chapter will focus on these key issues and debates, leaving the reader with a critical understanding of service user involvement with regard to its history, development and the nature of the challenges and opportunities that lie ahead.

Service user involvement – historical and policy perspectives

We can expect that so long as there have been human services, there have been pressures to make them more participatory from both practitioners and people on the receiving end as service users: to enable more equal two-way relationships, rather than the kind of bureaucratic and punitive regimes traditionally associated with poor law and regulatory regimes. However, it is really not until well into the second half of the twentieth century that we begin to see structured, formal and systemic arrangements come into existence that were expressly intended to encourage more involvement from service users and other citizens (Beresford, 2005). This marked a significant departure from the predominantly paternalistic and non-participatory ways in which, for example, post-war welfare states were established and operated.

There were two early and important contexts for this participatory development in the 1960s and 1970s. The first found expression in the US as the ‘War on Poverty’ and in the UK as the community development programme. Both were focused on communities and disadvantaged

groups, particularly Black and minority ethnic people, women and young people, and they sought to ‘involve’ people in challenging their deprivation by consciousness and skill-raising approaches. The second initiative was the implementation of provisions for participation, pioneered in the UK in land use and land development planning. The aim was for local people and communities to have a real say and stake in how their neighbourhoods and localities were shaped through involvement in schemes for public consultation and complaint in planning (Beresford, 2019a). These historic initiatives offer some early warnings about the possibilities and also limitations of adding such involvement to existing political and policy arrangements. We know that in the US and UK, the continuing existence of structural barriers relating to continuing (and in some cases worsening) economic and social inequality limited the capacity of programmes for positive discrimination either to engage or to uplift people effectively (Atkinson, 1983; Sheffield and Rector, 2014). Formal provisions for participation in planning have been notorious for their failure to engage large numbers of people and to address diversity effectively (Beresford, 2019a).

These problems are a reminder of the importance both of contextualising efforts to involve people and connecting them to broader political structures and ideological pressures and issues at work which may impact upon them. One approach has been to develop models of participation although these tend to be limited in their usefulness. Such uni-dimensional approaches to participation, while in some cases recognising power differences, often still struggle to address its essentially *political* nature. While they can have a helpful part to play in improving understanding, they also tend to be reductionist, over-simplifying and ill-suited to dealing with the real-life complexities and ambiguities of such involvement (Tritter and McCallum, 2006).

A more helpful alternative is to put such participation in the context of the development of modern democracy more generally. Here, four key stages in the development of public participation in health and social care and other policies and services can be identified. These historical phases are associated with:

- 1 Moves towards universal suffrage in representative democracy and the achievement of social rights, like the right to decent housing, education and health [first half of twentieth century, creation of welfare states in Europe];
- 2 Provisions for participatory democracy and community development;
- 3 Specific provisions for participation in health and social care [emerging internationally from the last quarter of the twentieth century];
- 4 State *reaction* and service user-led *renewal* as conflicts and competing agendas develop [emerging particularly in the second decade of the twenty-first century and problematizing more clearly international inequalities and Northern and Southern hemisphere differences].

(Beresford, 2019b)

We can see from this that the 1960s to 1970s examples we discussed earlier fall into the second phase. Significantly, we now seem to be in the grip of the fourth phase, where broader political shifts to neoliberalism internationally can be seen to have a reactionary effect against such participatory initiatives, while increasingly popular user- and community-led approaches continue to press – more overtly often – in the opposite direction. The contentiousness that this generates helps explain the particular interest in discussions like those contained in this book, as well as highlighting the importance and urgency of developing them at this time.

Although the dominance of neoliberal ideology has imposed limits on the development of user involvement and citizen participation, as well as on the rights and say of people as service

users, it would be a mistake to assume that it has ended progress. Indeed, what we can see is an increasing focus and indeed, in some ways, a strengthening and redirection of activity. Thus, while experiencing much suffering in recent years, service users and their organisations have extended both their critiques and their action in relation to health and social care and other policies and services. Some key areas of activity include:

- Widening involvement and campaigning, challenging exclusions
- Involvement in professional and occupational training
- Involvement in research and knowledge production
- The development of ‘Mad Studies’.

All of these areas of activity are explored in this Handbook.

Service user involvement – knowledge and theoretical perspectives

At the very core of involving service users is an essential recognition that this involvement in itself brings with it a particular type of *knowledge*. It is, therefore, arguable that a fundamental questioning and shift has occurred in what is regarded as knowledge in the domain of human services work (see Beresford, 2000; Beresford and Boxall, 2012; Levy et al., 2018). Inevitably, this has been seen as challenge to other types of knowledge regarded as more traditional and ‘expert’ and, implicit within this, a recognition that there are ‘other knowledges’ which also can make an equally important contribution. Rose, for example, argues that there can be no such thing as universal knowledge but instead differing knowledges from different standpoints should be recognised (2009). Linked to this, McLaughlin (2009), adopts the term *service user standpoint theory* to argue that service users occupy a particular *standpoint[s]*, and their experience of being social work service recipients facilitates their development of key insights, perspectives and understandings about these issues based on lived experience. Locating service user experiential knowledge within standpoint theory, defined as “theory based upon identity and, in particular, an individual’s membership of a particular social group, whether this is women, disabled people or service users” (p. 12), McLaughlin (2009) builds on the works of Harding (1987, 1991), Collins (1986) and Swigonski (1994). The basis of standpoint theory is that “less powerful members of society experience a different reality as a consequence of their oppression” (Swigonski, 1994, p. 390). Developing this argument further in regard to service user involvement in research in particular, Swigonski asserts that “less partial and distorted understandings of nature and social relations will result from research that begins from the standpoint of particular marginalised groups of human beings” (p. 390). Beresford (2013a) adopts a similar view in his argument that service users having an important contribution to make from their experience of being on the receiving end of social policies.

Service users and carers have thus had a well-established formal position in key aspects of professional social work education in the United Kingdom since its reform in 2002. In this role, their experiential-based knowledge has helped social work students in their understanding of social work values (Duffy and Hayes, 2012; Gutman et al., 2012), linking social work theory to practice (Brown and Young, 2008), developing skills in preparation for practice learning (Duffy et al., 2012) and understanding difficult, threshold concepts in the curriculum (Meyer and Land, 2005), such as the impact of political conflict (Duffy, 2012). Service user-based knowledge has therefore had an important, recognised role at the heart of preparing social workers for human services work.

As mentioned already, acceptance of service user, experience-based knowledge can pose epistemological questions and debates when compared to other types of knowledge considered

to be more objective, expert and scientific (Eraut, 1996; Fook, 1999). While Ramon (2003), for example, argues that service users bring valuable first-hand knowledge in terms of policy, practice and research, concerns about “ordinary people taking on powerful roles” express the types of fundamental challenge that face the gravitas of this knowledge (Rimmer, 1997, p. 33). Similar questions have been expressed by others, such as Prior (2003), who raises questions about lay knowledge being too subjective and lacking in wider applicability. The latter point, however, links back to Rose’s argument about the need to accept knowledges from differing standpoints, and to Harding (1987) and Swigonski’s (1994) contentions that there are different ‘ways of knowing’. It also challenges old assumptions that there is such a thing as ‘objective knowledge’ in the social sciences (Beresford, 2003).

Trevithick’s (2008, 2012) pioneering work on the key components of the social work knowledge base is also important in her positioning of service user knowledge within a *factual* domain of knowledge in social work. Similar to the points already mentioned about service users being directly impacted by social welfare policies, Trevithick argues it is important “to recognise and to acknowledge this pool of knowledge and to use this information creatively” (2012, p. 1226). Fundamental questions of power and power imbalances are inextricably interwoven with these processes, which will be discussed later in this chapter. The social work literature, for example, frequently negatively constructs service users in an ‘othering’ discourse as being in some way deviant and on the outside (Banks, 2006). Acceptance of service user knowledge is thus a fundamental challenge to such “anti-oppressive literature or theory” (Wilson and Beresford, 2000, cited in Beresford and Boxall, 2012, p. 161), which arguably has had a tendency to problematically portray perceptions of service users. Linked to this point, and important in this notion of comparing different sources of knowledge, there is an argument that all knowledge claims should be exposed to critical questioning, thereby promoting anti-oppressive practice (Dalrymple and Burke, 1995; Clifford and Burke, 2005).

Service user knowledge arguably also can align itself to well-established existing theoretical constructs, particularly the work of some critical social theorists. For example, pivotal to Recognition Theory (Honneth, 1996), according to Rossiter, is the argument that an individual’s identity is a social construct “socially acquired and thus identity is a matter of justice because the acquisition of self-confidence, self-respect and self-esteem is the foundation of autonomy and agency” (2014, p. 93). Honneth therefore situates identity development as linked with the role of others, which will ultimately help with the promotion and advancement of social justice. “It makes you realise how much you have to share” (Duffy et al., 2012, p. 12) is arguably an extension of Honneth’s thinking in practice. Here, a service user expresses confidence in the knowledge that lived personal experience is brought to bear in assisting social work students in their knowledge development. Such a comment also accords with Cotterell and Morris’ (2012) observation about the lack of confidence that marginalised individuals can sometimes attach to the value of their lived experiential knowledge (Duffy, 2015). Facilitating opportunities for involvement, espousing Recognition Theory, thus can not only connect firmly to established social work values but also facilitate an emancipatory and social justice-based dialogue. Paulo Freire’s seminal *Pedagogy of the Oppressed* (1972) quite makes the point: “only a critical consciousness of the knowledge in one’s possession can in turn lead to action and transformation” (cited in Cotterell and Morris, 2012, p. 60).

Service user involvement – power perspectives

Traditionally, helping services have often been rooted in an unequal distribution of power, with service users placed at a disadvantage. To make matters even more complex, they often

intervene in the lives of people who are already disempowered or going through disempowering experiences in their life. While the focus of such 'helping' services has tended to be on the individual changing themselves, service users, their organisations and movements have also been concerned with changing those services themselves as well as the wider worlds in which they themselves live. If there is one generalisation that seems to hold irrespective of when and where research is undertaken, it is that service users get involved to change their and other people's lives for the better. To do this, they need to be able to have power, know that they have it and be able to make use of it.

The political sociologist Steven Lukes developed the idea of three dimensions of power. The third dimension refers to the social construction of practices, ideologies and institutions that secure people's consent to or at least acceptance of domination (Lukes, 2004). Community and developmental educationalist John Gaventa drew on this to support approaches to social change rooted in the perspectives of marginalised communities. Instead of looking for the sources and solutions of social problems in the theories and ideas of social science and social policy experts, he validated the narratives of the oppressed populations involved. In Gaventa's theory, such methodological subjectivity makes it possible for the framing of a social problem and its solution to arise from within the group. This both has an empowering effect on the group and provides a basis for it to take collective action to challenge dominant discourses and develop alternatives (Gaventa, 1982).

When it comes to people's involvement, power issues operate at both a macro and micro level, and service user involvement is impacted by both. Thus, at a macro level, there are the insidious impacts of neoliberal ideology and its associated managerialism. Their values, based on individualisation and regressive redistribution of wealth and opportunities, collide with those that underpin and are core to the emancipatory involvement sought by service users. The devaluing of service users' 'lived experience' and 'experiential knowledge', compared to traditional knowledge deemed more 'scientific', 'objective' and reliable, can be seen as another manifestation of such macro power. This both deters service users from feeling valued and getting involved and places significant barriers in its way. At a micro level, we can see how power imbalances are expressed through tokenistic approaches to involvement, which fail to address diversity with equality: the box ticking culture, creation of consultation fatigue, lack of sensitivity to practical considerations of physical, communication and cultural access.

At the same time, we now have many international examples of how such exclusionary and negative ideological and organisational pressures can be challenged and overcome. This book brings together many such examples. One such is PowerUs, which is showcased in this book, where an equalising of power relationships between educators, students and service users, building trust and shared understanding, can result in really productive and innovative outcomes in education, which have lasting effects for more equal and effective practice (Askheim et al., 2017). Also reported later in this book is pedagogic research undertaken in Northern Ireland with victims and survivors of political conflict, which has clearly evidenced the positive impact on students' knowledge skills and values by being directly introduced to these important personal lived experiences in the classroom (Duffy, 2012; Coulter et al., 2013; Campbell et al., 2013). These types of innovations in social work education would have been unthinkable during the 'Troubles' (the term used to describe over 30 years of violent political conflict) but were positively aided by the wider peaceful societal milieu heralded by the Northern Ireland Peace Agreement in 1998. Working in close partnership with citizen educators who have lived through and been adversely affected by violent political conflict has yielded important learning outcomes for social work students. Central to the success of this initiative, however, has been the value and respect given to experiential knowledge and the important contribution that this

can provide. Without this, these significant achievements would have been impossible. Other international contexts are also evidencing ways in which students are learning from service user knowledge. The literature provides examples from the US, Middle East and Europe of ways in which service users and academic staff work together in helping students to understand the impact of living with mental ill-health (Gutman et al., 2012), and there are notable innovative examples also of students and service users studying alongside each other (Kjellberg and French, 2011).

Service user involvement – challenges and opportunities

We are now arriving to the final part of our chapter, where we can think positively yet realistically going forward about the key challenges that lie ahead and how these can be turned to opportunities. We will of course be reflecting back on the key messages from the three preceding sections, but we will also signpost readers in an important way as to what can be achieved when service user involvement is approached through the critical lens that our chapter is advocating.

While there is much more still to be done, there seem to be some key lessons from all the experience we already have from the development of user involvement in professional learning and education. We know there are challenges, but there are also real opportunities.

The first thing to work for is clarity. This is not necessarily easy or straightforward, given that user involvement is a relatively new idea and a common language can obscure very different assumptions, understandings and intentions. So, we must try in all we do to be clear. What kind of involvement is on offer? Is it just to hear what people have to say: perhaps their concerns or complaints or misgiving? Or is the plan really to try and listen to these and do something about them? That really is the key point, because we know that people really want to be involved to make a difference, for their views both to be heard and acted upon. Not many of us are content with just hearing the sound of our own voice! We want it to have an impact, bring about change, make things better.

And that brings us on to another key issue: how we can be involved. It has to be in ways that work for us: which feel familiar, comfortable and are appropriate, rather unfamiliar, inaccessible and perhaps even intimidating, such that we are reluctant to express our true opinions. We must feel safe. We must have encouragement to feel as confident and assertive as possible. We need to be offered a sympathetic setting and good conditions for our involvement, without hidden and unmet personal or financial costs. Involvement must be accessible regardless of our particular access requirements, communication needs and so on (Beresford and Croft, 1993).

Which leads to an even broader issue – ensuring that as wide a range of people can get involved as possible. We know from existing participatory arrangements that many groups face barriers of one sort or another, which means that they can readily get left out. We have to work to challenge those barriers and exclusions (Beresford, 2013b).

Conclusion

Participation, user involvement in one sense, is not rocket science. It doesn't demand vast amounts of specialist knowledge or special qualifications. Some might say it is mainly a matter of taking trouble and common-sense. That might in one sense be true, except many service users might conclude that there is a very common lack of common-sense around if that is the case, because they have so many experiences of poor and unpleasant involvement. Perhaps this really means two things. First, we have to be committed to involving people as positively and

inclusively as possible. Second, as with any serious activity or new venture, we have to check out what other people have already done and learnt and what we ourselves have learnt from that, instead of rushing in where angels might fear to tread! We have to take trouble; we have to be serious. And, of course, we will have to allocate a sensible budget – as with any activity – to ensure that things work out well. And, finally, we need to keep people posted about what has happened and what has been learned. That is the key next step. And it is almost, but not quite, the last step. Because that, as we have already heard, is to make sure that what people say is acted upon! Involvement and action should be seen as inseparable. Involvement is not some kind of academic exercise. It is about real change for the better in real people's lives, in the real world. And working for such change in professional learning and practice, based on service users' experiential knowledge and lived experience, is clearly at the heart of this.

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