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SERVICE USER INVOLVEMENT IN RESEARCH

What difference does it make?

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Introduction

From very humble beginnings, user involvement in research and user-led research have increasingly impacted on political, policy, professional and public understandings about the nature, methods and purpose of research. This development has been international in its influence and spread. However, as this book shows, its growth is neither assured nor universal, as Alam (2020) documents about the US, Cirano (2020) about Spain and Pouo about Congo Brazzaville.

In this chapter, we will try to look particularly at what difference these developments have made. But, in doing so, we must not only avoid any desire to over-claim for them – this is work still very much in progress – but also equally avoid glossing over the complexity and uncertainty of progress in this field. It is important to remember that the pressure for greater user involvement in, and indeed leadership of, research can now be traced back to the 1970s – nearly half a century. This is no new discovery. But it is also one that arguably is transformative in its implications and effects and one which opens the door to new paradigms in many domains, from knowledge formation through professional development to transforming social and public policy.

There have been distinct phases in the development of user involvement in research, just as there have been more broadly in the development of participatory initiatives in states and societies. We will begin with the first of these, the emergence of emancipatory disability research and its implications, emphasising their incapacity and reinforcing their marginalisation.

What research is for

Through the first half of the twentieth century, prevailing understandings of disability were predominantly individualised and medicalised – it was seen as an isolated personal tragedy, and the response was primarily one of segregating disabled people and lumping them together as defective (Oliver, 1983; Hunt, 2019). In the UK, a group of institutionalised disabled people sought to challenge this, believing that with the right kind of support, they could lead independent lives in mainstream society. They approached a group of social researchers to evidence their ability to live independently but were then shocked when these researchers wrote them off as ‘social parasites’ who would inevitably be dependent on society (Beresford, 2016, pp. 218–219; Hunt, 2019). This was a turning point in disability research. It led disabled activists to feel that if they wanted research which truly reflected their experience, situation and interests, then they must carry it out and control it *themselves*. Such research became an important part of the emerging international disabled people's movement and was seen as a form of collective self-advocacy. Key characteristics of such research were that it would:

- equalise relationships between researcher and researcher;
- be empowering for research participants;
- lead to political and social change in line with the interests of disabled people;

and was

- not only participatory, but emancipatory in purpose.

As Mike Oliver, the disabled academic and activist, wrote, this was a different kind of research to that of the mainstream:

> the research is not an attempt to change the world through the process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before.
>
> *(Oliver, 2009, p. 116)*

This is a fundamental distinction to draw. Such a philosophy, with its purpose of democratising research and directing it to the empowerment and liberation of oppressed people, has developed more broadly into user-controlled and 'survivor' research as more groups have taken it forward, particularly in the twenty-first century.

However, the pressure for change in research also prompted a response from research itself. This has been reflected in a growing range of formal requirements for participation, or what has become known as 'public, patient involvement' (PPI) in:

- accessing different sources of funding, both statutory and non-statutory;
- planning and undertaking research projects;
- disseminating their findings and acting on them.

Perhaps most important was the establishment of what became known as the National Institute for Health Research (NIHR) INVOLVE (www.invo.org.uk/resource-centre/) in 1996 to support and encourage involvement in health, public health and social care research. Over this period, we have seen such participation extend to processes of research governance, research organisations, peer-reviewed journals and other research publications, as well as to research conferences.

While Director General of Research at the Department of Health, Dame Sally Davies stated:

> I have always taken the view that public involvement in research should be the rule not the exception. It is fundamental to ensure high quality research that brings real benefits for patients, the public and the NHS.
>
> *(Staley, 2009, p. 14)*

Increasingly, service users have been able to gain research qualifications (pioneered by the Centre for Disability Studies at the University of Leeds, initially established in association with the UK disabled people's movement), with growing numbers gaining PhDs and entering academia and research organisations as researchers. This reminds us that being a service user, or a researcher, is not a mutually exclusive identity; it is possible to be both.

The increasing numbers of service user PhDs entering academia and research organisations are significant developments. However, they should not be exaggerated, and there is no doubt that progress has been patchy and inconsistent, with the achievement in some areas, organisations and academic and research institutions much more substantial than in others.

Of course, the key question, and the one which this chapter asks, is: what difference does involvement in research make? We know from service users that whenever they are asked why they get involved – whether we are talking about research, policy or practice – they say it is to make a positive difference and bring about real improvements in people's lives, in line with their rights and needs.

We also know that the major complaint from disabled people and service users is that invitations to get involved are often no more than tokenistic, and seem to be for a researcher to tick a box in a research proposal. There are widespread feelings that decisions have often already been made when they are asked and that frequently little notice is taken of what they say they want (Beresford and Croft, 1993). It is important to recognise that service users usually have no say in prioritising what the research question is and are often recruited after this has been decided. But there is more to this issue than a reluctance on the part of some services and policymakers to take user involvement seriously or variations in enthusiasm and commitment, although it is often explained in such terms.

At a more profound level, what we are also seeing is the working out of different, competing ideologies in relation to participation and user involvement which can be explained by the conflicting origins of pressure for this development over the period in question.

As we have seen, this originated with people on the receiving end of public policy, particularly marginalised groups like disabled people and mental health service users/survivors, seeking to redress what they experienced as an imbalance of power by working for more say and control in policies and services which affected them and their lives. They can be seen as in the same tradition and reflecting the goals of other new social movements like the women's, Black civil rights and LGBTQ movements. Their aim has been to democratise public policy and services, redistribute power downwards and remake provision in to serve a liberatory and supportive role.

At roughly the same time, government and service systems and associated research institutions have been developing their provisions for participation, usually in the form of consultative market research and related provisions. But here there has generally not been any suggestion of redistributing power. Instead, developments have more clearly come within a consumerist framework tied to a market-based model. Thus, the involvement, views and contribution of service users are sought, just as they are with conventional commercial goods and products to maximise their knowledge-base, marketability and profitability through inputting the views, intelligence and preferences of service users. This is essentially a process of extraction rather than empowerment. Control remains where it has always been: with those making the decisions about what notice to take of service user input. To put it in conventional market terms, being asked your views is far from the same as being offered a place on the board.

In our view, here lies the origin of the major misunderstanding in conventional provider-led approaches to involvement. It is a misunderstanding that has played a major part in stymying user involvement. Being asked to give your views is not the same as having a direct say in decision-making, and it is the confusion between these two different approaches and offers that has led to much user frustration and accusations of tokenism and 'rubber stamping' in participatory arrangements. What is needed, therefore, is greater clarity in what kind of involvement is being offered, so that service users and their organisations can decide if it is an offer they want to accept, ignore or challenge. The fact that consumerist and democratic approaches to involvement – in research as elsewhere – are couched in very much the same language has of course increased the confusion and misunderstanding. It is therefore important to attempt to be clear about differences in values, aims and objectives when it comes to user involvement. Failure to do that is only likely to result in misunderstanding and distrust.

This situation is made all the more difficult as we have come to accept an increasingly neo-liberalist hegemony and continued government chosen austerity (Jones, 2018). This has led to increasing individualism and reduction in the welfare state and state benefits coupled with rising eligibility thresholds. In the UK, this has led to the UN Special Rapporteur on Extreme Poverty and Human Rights to claim that 'British compassion for those who are suffering has been replaced by a punitive, mean spirited, and often callous approach' (Alston, 2018, p. 3). This makes it all the more important that service users contribute to prioritising research questions and act as researchers and co-researchers in addressing key questions of design, delivery and effectiveness of human services provision.

Research is about finding things out, whether it's focus is on us or our wider world, and trying to do so in the most reliable, consistent and accurate way possible. However, what we have been learning throughout this book, and during the course of this particular chapter, is that we can come at this from many different vantage points, with diverse, sometimes competing concerns. So, we need to be clear in advance not only what kind of involvement in research is under consideration but also, *whose* knowledge is research primarily concerned with revealing, making available and to whom? Historically, research was primarily intended to prioritise the expert knowledge of policymakers, professionals and politicians. Since the advent of user involvement, a new concern has arisen: to identify, make available and act on the knowledge of people traditionally on the receiving end of public policies, services and professionals, that is to say, their experiential knowledge – the knowledge emerging from their lived experience (Sweeney et al., 2009). This knowledge is essential to understand and respond effectively to the issues and challenges of those in receipt of services, as it is only they who experience both the intended and unintended consequences of public policies, services and professionals (Beresford, 2000). To ignore this perspective is to negate any identified recommendations for change as at best partial and at worst mis-informed.

Thus, we really need to be clear whose knowledge we want to bring to the fore, recognising that if there's one thing user involvement has taught us, it is that the search for knowledge can be a battleground. Put simply, the big pharma want to mine user knowledge about their mental health drugs for very different reasons to many service users themselves. And as a result, findings and conclusions can be very different. This was the clear finding when, for the first time, a systematic review with user involvement was carried out on Electro Convulsive Therapy (ECT), a very contentious 'treatment' long used on some mental health patients. Instead of the unproblematic findings of much traditional research, serious problems were identified in this study in the administration by professionals of this procedure (Rose et al., 2003). Once we recognise that the great opportunity offered by user involvement in research is to include the experiential knowledge of service users, then we have the chance of maximising its potential as an agent of change.

Importance of including all perspectives

A major reason for making additional specific provision for eliciting the views of people as health, care and other professional service users is because of the increasing view that their views have not emerged from the conventional processes of representative politics and thus additional efforts were needed to elicit them. Pressure for involvement in public services and professions arises from the sense of a gap or shortcoming in mainstream democratic arrangements. But as we have developed our skills and understanding about such user involvement, so we have also come to appreciate that it can have its own limitations. The 'Beyond the Usual Suspects' project carried out by Shaping Our Lives with funding support from the UK Department of Health highlighted that many people continued to be marginalised in such participatory initiatives. These included:

- Equality issues: in relation to gender, sexuality, race, class, culture, belief, age, impairment and more;
- where people live: if they are homeless, in prison, in welfare institutions, refugees and so on;
- communicating differently: if they do not speak the prevailing language, it is not their first language, they are deaf and used sign language etc.;
- the nature of their impairments: which are seen as too complex or severe to mean they could or would want to contribute;
- where they are seen as unwanted voices: they did not necessarily say what authorities want to hear, are seen as a problem, disruptive etc. (Beresford, 2013)

Only when serious efforts are made to include these neglected, often devalued, perspectives can user involvement in research make its potential difference for everyone, rather than just those whose experience and identity match groups valued more in society. This demands that for service user involvement to be taken seriously, researchers need to be believe in the added value of such an approach, be committed to a process of learning that will require time, effort and funding for service user's time, which is not always going to proceed smoothly and is likely to challenge hierarchies and power dynamics (see Natland, 2020, in this volume). However, for us, the potential for better, greater quality research and its meaningfulness for those on the receiving end of services more than makes up for the effort required.

Conclusions

As the many chapters in this book ably illustrate, there is a wealth of knowledge and skill in working participatively with different client groups in a range of different settings in different countries. By bringing together this collection of experiences, we hope we will inspire others to join us: service user, researcher, service user researcher or whichever identity you wish to claim. If we accept that differing knowledges and experiences contribute to a fuller understanding of human services issues and challenges it then becomes essential that we embrace the experiential knowledge of service users otherwise any claims to a full understanding of a research problem will be inherently untruthful. Service user involvement in research can and will make a difference; however, it is precarious in many countries, while in others it is yet to be viewed as a legitimate form of research. On top of this, we have already noted that it can be tokenistic, and we need to continue to strive to ensure that it is meaningful, and that we collect examples, like we have in this book, where it has made a positive difference and brought about real improvements in people's lives – that is the challenge!

References

Alston, P. (2018), *Statement on the Visit to the United Kingdom, by Professor Phillip Alston, United Nations Special Rapporteur on Extreme Poverty and Human Rights*. www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf

Beresford, P. (2000), 'Users' knowledges and social work theory: Conflict or collaboration', *British Journal of Social Work*, 30 (4), 495–503.

Beresford, P. (2013), *Beyond the Usual Suspects: Towards Inclusive User Involvement – Research Report*, London, Shaping Our Lives.

Beresford, P. (2016), *All Our Welfare: Towards Participatory Social Policy*, Bristol, Policy Press.

Beresford, P., Croft, S. (1993), *Citizen Involvement: A Practical Guide for Change*, Basingstoke: Palgrave Macmillan.

Hunt, J. (2019), *No Limits: The Disabled People's Movement – a Radical History*, Manchester, TBR Imprint.

Jones, R. (2018), *In Whose Interest? The Privatisation of Child Protection and Social Work,* Bristol, Policy Press.

Natland, S. (2020) "Recently, I have felt like a service user again": Conflicts in collaborative research, a case from Norway, in McLaughlin, H., Beresford, P., Casey, H., Cameron, C. and Duffy, J. (eds.), *Routledge International Handbook of Service User Involvement in Education and Research*. Abingdon, Routledge.

Oliver, M. (1983), *Social Work and Disabled People*, Basingstoke, Palgrave Macmillan.

Oliver, M. (2009), *Understanding Disability: from Theory to Practice*, Basingstoke, Palgrave Macmillan

Rose, D., Wykes, T., Leese, M., Bindman, J., Fleischmann, P. (2003), 'Patients' perspectives on electro convulsive therapy: Systematic review', *British Medical Journal*, 326, 1363–1366.

Staley, K. (2009), *Exploring Impact: Public Involvement in the NHS, Public Health and Social Care Research*, Eastleigh, INVOLVE.

Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., Rose, D. (editors), (2009), *This Is Survivor Research*, Ross-on-Wye, PCSS Books.