

# Guest editorial

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## **If you want to walk fast, walk alone. If you want to walk far, walk together.** (African proverb)

Over the last three decades, the involvement of service users and family and friends in mental health services, education and research has moved from the campaigns and struggles of a few marginal voices to something that is now expected to occur in the UK and is gaining momentum internationally. Despite this broad shift from the margins to the centre of mental health practice and discourse, service user and family involvement remains a decided work in progress. On the one hand, it seems straightforward, even obvious, that the involvement of the people that use services in service development, training and research will improve the quality and relevance. At the same time, the introduction of service user and family voices and priorities into practices, formerly based on actively excluding them, has not been without its practical, methodological and epistemological challenges. Running throughout all of these issues are practical and political questions, around how to make time and resource available to do more than tick the box on involvement and how to measure the impact of so doing.

The six papers in this special edition address these challenges in different ways. We have divided them into two sections for convenience. The first section is focused on involvement in service delivery and the training of mental health professionals and the second on public and patient involvement (PPI) in research. However, it should be noted from the start that this division is quite arbitrary. Questions of power, politics and pragmatics intersect across involvement in all of the forms of knowledge production discussed throughout.

### **Involvement in service delivery and training**

Freeman *et al.* open the collection with a truly hope-inspiring narrative account of developing a recovery and rehabilitation service in a secure forensic setting. Using Arnstein's ladder of citizen engagement (1969) and the "4rs" (role, remit, relationships and responsibility), the authors develop a model to describe three key steps to bring about the culture change needed for a co-production service to flourish. Arnstein's ladder is often used to illustrate the aims of co-production, as one of moving from a relationship of "doing to" people, past one of "doing for" onto one of "doing with". In Freeman's account, listening to and valuing the expertise of lived experience is a key first platform for developing the confidence and empowerment for service users to embark on the second step of training staff to work in different ways to bring about the third step of genuine partnership. One of most inspiring things about this account is that the authors do not claim to be already doing co-production or use it as an empty buzzword. Rather than describe co-production as something already achieved, they meticulously describe a process of moving from a position of very little involvement towards the goals they desire to embed organisationally.

The process described by Freeman *et al.* is clearly initiated by professionals, but also documents a desire to share power and responsibility. While this may all sound quite idealistic, the authors are also pragmatic about obstacles and setbacks as part of the process. Nor do they underestimate the scale of the task. By framing their journey as climbing Everest, the authors acknowledge that culture change does not come about overnight and may be a slow hard slog, summed up in the phrase that "if you wish to walk fast, walk alone" which is the title of this editorial. Further, as the authors also suggest, reaching the summit also involves descent on the other side and many more mountains to climb in a much longer open-ended process. As such, their contribution is an invaluable practical aide for anyone seeking to bring about cultural change in a service setting and looking for a place to start.

Our second paper is much more ambiguous. While Freeman *et al.* supply a clear road map for co-production, Lea *et al.* point out that there is no standardised measure to show how, or if, involvement of lived experience experts in the training of mental health professionals improves quality of care further down the line. To begin the process of creating such a measure, the authors offer a qualitative analysis of the perspectives of staff, students and lived experience experts within a clinical psychology teaching programme. Their findings are both cause for optimism and concern around walking far together. On the one hand, the importance of remaining human emerges as a key learning outcome for trainees. Involving lived experience experts enabled trainees to understand their own prejudices and to start to look past diagnostic labelling to the person in the room. On the other hand, service users and staff are shown to hold very different priorities around training outcomes. For the former, trainees should go on to be beacons of hope and recovery for service users, once qualified. For the latter, acceptance that the mental health system damages people was seen as a core part of the learning needed to become a professional clinical psychologist.

It is perhaps not unsurprising, although deeply worrying, that clinical psychology trainees with lived experience of using services were left in a double bind, able to explicitly value the learning received from lived experience colleagues but simultaneously confused about why they could not openly value their own lived experience of mental health distress within their training. While the authors consider possible further research and dialogue, the implications are that organisational understandings of professional competency remain at distinct odds with the invocation to remain human in a shared learning encounter. However, these conclusions also point to a fundamental question around the politics of the education of health professionals and the capacity of lived experience experts to be agents of change.

Who is this human? Walsh offers the most theoretical contribution to our understanding of how power politics and narrative identity are negotiated in learning environments. The author takes a post-structural approach, combining analysis of the multiple discourses which shape the personal and professional identity of occupational therapy students, lived experience experts and course tutors as contested sites of power, knowledge and legitimate speech. Walsh draws on Foucault, in particular, to extract a range of metaphors which position lived experience speakers in relation to students and tutors. Here, identity is not something pre-given and fixed, nor is power understood as something wielded like a hammer from one person to another, although this is certainly one way power can be expressed. Rather, identity is understood as something both created and fluctuating within multiple narrative contexts, in which power produces visible and invisible realities. This is an inter-subjective process impacting on both the content and style of the narratives. For example, service users reported modifying their narratives because they did not want to upset people. While using direct experience was often an empowering experience, one of the key contributions of this paper is to show how more hidden aspects of language and power could impact on who gets to speak in such environments or construct speakers as “tame nutters” shoring up the power imbalances already present in learning environments.

### **Involvement in research**

The themes of impact, power and knowledge are played out in the three papers which form the second half of this collection.

Croft *et al.* open this section with a case study of the employment of peer support workers as interviewers in the revaluation of a peer support service in a North American context. Here the research gains appear to be straightforward. The response rates of the survey conducted by peers were much higher than expected for a study of this type, suggesting that service user researchers do indeed add quality to some kinds of data collection. Benefits to the peer researchers included opportunities to develop careers, which might not otherwise have been available. However, the story was not always rosy regarding the impact on service user researchers themselves. Croft *et al.* document difficulties in managing the time and pace of the research process, causing some peer researchers to drop out. Not all peer researchers were happy about the survey questions, suggesting that lived experience not only needs to be embedded in conducting research, but more deeply within the methodological design of the study itself.

The question of methodological mismatch between lived experience and research experts and related questions of time and pace are central to involvement in the REFOCUS project described by Slade *et al.* REFOCUS was the first large research project funded by the National Institute for Health Research to attempt to build a conceptual model and form of intervention for refocusing service delivery on recovery orientated principles.

The authors describe a journey which started with much controversy around the exclusion of black and minority ethnic (BME) perspectives to maintain cross cultural validity in the planned randomised control trial, leading to the resignation of a BME member of the lived experience advisory panel (LEAP). Remaining members of LEAP set up a critical friendship model of involvement and asked that all decisions and actions be documented in an involvement log so that any tokenism would be transparent. The study team responded to these challenges by developing a new study focused on recovery for BME service users, leading to the return to LEAP of the BME member who had left. The involvement log itself showed that the LEAP group had made a definite impact on the conduct of the study defined within the methodological perimeters of a randomised control trial, but this needed to be balanced with unplanned time and resource for the study team to respond.

These tensions aside, the case study also documents a broad shift in emphasis from consultation to co-production as trust between LEAP and the study team developed. In particular, LEAP members led the write up of the final study report and then extended an invite to the chief investigator to reframe the narrative from his perspective for this special edition as his perspective had become marginalised in the process. The implications of this journey are manifold and we leave it to readers to weigh them up. Nevertheless, one of the strengths of this account is to document co-production in research as a hard won and non-linear process, fraught with dissonance between research methodologies and exclusions built on positivist understandings of objective knowledge and the very positioned nature of dialogue with lived experience experts. REFOCUS offers a rich learning encounter, suggesting that for co-production to genuinely occur there needs to be willingness from all parties to experience some discomfort in the process.

Our final contribution from Gillard *et al.* is perhaps the most methodologically creative and daring. Working from the start point that PPI is a complex intervention, the authors offer a conceptual framework for co-production as a way of closing the implementation gap between research and service development. The stakes are high for it is a huge and well-founded criticism that much research, carried out at great expense to the public, never finds its way into practice. Drawing on implementation science, the authors offer thematic analysis of a systematic literature review, which is then used to retrospectively analyse a previous study looking at peer support. Five PPI domains are identified as follows: relational modes of knowledge, the importance of recognising experiential knowledge as legitimate knowledge, collaborative practice, knowledge facilitation and implementation context. While more research may be needed to test the conceptual framework, the editors note both the striking similarities and overlap between these domains and the model of co-production informing our opening paper. This, and the centrality of changing what counts as legitimate knowledge in research suggests that it is dialogue with experiential knowledge that is transformational of what we know, how we know and, in turn, how to turn new knowledge into further practice change.

## Concluding remarks

It has been a great privilege to edit this special edition. For both editors, the collection attests to much ground travelled from early debates focused on “if involvement should occur” to debates focused on “how it occurs and the strengths and limits of this”. Yet, to repeat the climbing Everest image of our first contribution, we may still only be at base camp with many rock faces to climb. Within services, environments supportive of co-production do not spontaneously emerge and can be difficult to sustain in organisations, which remain saturated by command/control hierarchies. In academia and research, power differentials between the knower and the known are played out through struggles around what counts as legitimate knowledge, complex negotiations within narrative identity and indeed whose voice, if any, can speak at the table. While involvement may have become more mainstream in mental health services, there are still plenty of

service user and family voices marginalised by mainstream service users. Only one of our contributions has touched on BME perspectives and none have considered other factors that make up a person's identity as a lived experience expert or addressed the thorny question of power imbalances between experts by lived experience.

Despite, and perhaps because of these limits, the combination of practical and theoretical perspectives throughout suggests to us that the time is now ripe for service user involvement to do more. As with other social movements before it, there is now a pressing need to critically reflect on the very embodied exclusions that are made in the name of inclusive practice. If when "we" collaborate, "we" collaborate with people who sound just like "us", one normative cultural dominant has simply been replaced with another, with all the new exclusionary practices this entails. The recent emergence of Mad studies, in particular, could thus not be better timed as an academic service user-led discipline committed to the theoretical expression of some of the political and philosophical issues touched upon here.

Nothing less is at stake than what it means to be a human being. We do not pretend to have either the first or last word in this enormous philosophical question. Our more humble aim has been to offer readers some sense of the pleasures and pitfalls of service user involvement from a range of perspectives. Nevertheless, we would also conclude that one of the things demonstrated by this collection is that non-academic grassroots involvement activities also lend themselves to a collaborative praxis, where differences can be held together in the creation of something new and unknown. Neither academia nor the grassroots could or should have the monopoly on knowledge creation. Rather this collection suggests that it is the combination of different kinds of knowing which hold the potential to unlock the binary oppositions and knowledge silos which keep mental health professionals and lived experience experts alike "stuck" in outdated knowledge hierarchies and top-down practices. Dismantling these knowledge silos and hierarchies opens onto an uncertain future and for us this could be a good thing. Of one thing we are sure, it is just not possible to simply add lived experience and stir within the institutional discourses shaping existing mental health knowledge and practice. The very activity of introducing voices that have previously been invalidated changes the nature of the place.