

Peter Beresford

## **Including the Knowledge and Perspectives of Service Users**

### **NOT TO BE QUOTED WITHOUT ACKNOWLEDGEMENT**

First can I say how pleased I am to be part of this seminar. I think it is an important event because it provides an opportunity to influence and hopefully reset agendas, something that is especially important at this time of change in health and social care, as well as in society more generally. That links with a second point I feel I should make. The Natural History Museum is I think an especially appropriate place and this year with the bi-centenary of Charles Darwin's birth, an especially appropriate time, to be having this discussion. Because I believe that the least we have the chance to do here, is to discuss the need for *evolution* in the health and social work/social care – with our particular focus on social work and social care research for the health agenda.

And perhaps more than there is a chance to be rethinking it in a more revolutionary and radical way. My focus follows from including the knowledge and perspectives of service users and I believe this offers us one helpful route to a more radical critique and understanding of issues that may confront us here.

Let me begin by saying a little bit more about myself, so you know better where I am coming from. I work at Brunel University where I

am responsible for one of the University's established research centres, the Centre for Citizen Participation. We carry out consultancy, research and development work, taking forward participation in both the process and focus of what we do. I work alongside other service users as well as other academics, policymakers, practitioners and so on. I am committed to multiple perspective working. I am also committed to user controlled initiatives and activities. I have direct experience as a long term user of mental health services. I am also chair of Shaping Our Lives, the independent, national user controlled organisation and network. Please google us and visit our website ([www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)).

We are all service users in Shaping Our Lives. What is also important for us is that we make up a wide mix of service users including older people, disabled people, people with learning difficulties, living with HIV/AIDs, people who have had alcohol and drug problems, users of palliative care services, mental health service users and so on. Also we seek to work with a similarly wide range of service users. We don't want to perpetuate the bureaucratic distinctions that are made between people and which don't reflect the realities of people's complex lives and identities. We carry out research and also work to improve the say people have over their lives and the control they have over services. We also place a big emphasis on being inclusive, addressing diversity and ensuring that all service users have as equal a say, as equal access to our activities our decision-making structures and to the material we produce as possible. So we work hard to address diversity both in terms of challenging barriers

following from gender, sexuality, age, disability, ethnicity, sexuality, culture, class and so on and also barriers facing service user groups identified as facing particular exclusions, like homeless people, asylum seekers, people who communicate differently, with multiple impairments, in institutions, in the prison system and so on.

Shaping Our Lives has worked hard to have strong links at several levels – which I think is relevant to today’s discussion. First at ground level with service users and their organisations and second in key central government level policy organisations. For us this is crucial if we are to make possible grassroots change that can exert effective policy influence. So we have learned we have to engage in both bottom up and top down processes of change and work for their unification and reconciliation.

In my abstract I noted that I would be exploring issues raised by and seeking to engage with, the knowledge and perspectives of service users in relation to Social Work and Social Care Research for the Health Agenda. It is important for me to emphasise this point. I am concerned with enabling the inclusion of knowledge and research that relates to lived or direct experience; the experiential knowledge of people as service users and the collective knowledge of their organisations and the knowledge following from research that involves people as service users, both individually and collectively. So to return to my earlier point, in Shaping Our Lives, we have learned that we need to connect with key statutory bodies concerned both with research and with policy and practice – if we are to exert

influence through service user knowledge and experience. Thus, to give examples of this, I am fortunate enough to be a member of the National Institute for Health Research Advisory Board, working for patient and user involvement in health and social care research at an important level and also a member of the Department of Health's Transforming Adult Social Care Programme Board, which has an overview responsibility for rolling out personalization across social care. We need to be in such places to influence policymakers as well being alongside other service users.

So why first is it important to be engaging and including service users knowledge in agenda shaping here? What does it have to do with social work and social care research for the health agenda. I am going to use some examples in what I have to say and here comes my first one – mental health research, policy and practice. Let's start with this area of policy. Mental health policy and practice includes strong health and social care elements. Yet we know that it is still dominated by the medical model and by medically based interventions, primarily drug therapy – the dominance of both research suggests service users find unhelpful. In 2003, NHS R and D organized a national review of mental health research priorities. This highlighted – and this can be seen routinely still - by the big research projects going on the Mental Health Research Network, that mental health priorities are still largely medicalised and individualized in focus, looking for treatment solutions for individuals and this is how researchers still seemed to see the future. This review however also included a national consultation with mental health service users.

Significantly, their research priorities were radically different, far more social in orientation concerned with the barriers and broader issues operating in people's lives, both leading to and perpetuating madness and distress. The indications from this exercise, borne out by other experience, is that involving service user perspectives tends to strengthen recognition of social issues and relations, the role of social care as well as the role of medical models and traditional health approaches.

For my second case example, I want to turn to palliative care and findings from the large scale UK wide qualitative research study Suzy Croft, Lesley Adshead and I undertook (op cit, 2007), focusing on what service users want from specialist palliative care social work. Our first focus was on social work practice and we learned of the high value that service users placed on this area of social work practice. But broader issues also emerged and I want to focus on one that is highly pertinent to us today. Perhaps not surprisingly, we learned that social work was subordinated in palliative care, which despite its holistic traditions and aspirations seems increasingly medically dominated. This was recently reflected in the inadequate attention paid to social work and social care issues in the government's End of Life Strategy and the limited priority attached to them. Two other issues emerged strongly from our study. The dominance of a medical model and failure to understand the significance of social issues and approaches created barriers to successful inter-disciplinary, inter-professional working. But it also meant that service users' needs would not necessarily be quickly or adequately recognized. Thus

while service users greatly valued social work support, only a minority were getting referred for it and then often on the basis of judgements about their medical condition and its severity, rather than on the basis of their social or psychological situation, which was often why they most wanted and most valued social work support. Again service users and research involving service users was highlighting the centrality of social work and its social understandings and agenda in a health context which had difficulty adequately appreciating them or internalizing them.

Finally I want to consider disability in relation to our focus today. Forty years ago disability was primarily a field understood in medical terms, researched by medical sociologists and most closely associated with medical interventions, segregated education and institutions. Now the social model of disability and the philosophy of independent living have been incorporated into government policy, there is equalities and anti-discrimination legislation which includes disability rights, bodies are subject to disability equality duties and the government as I have mentioned is rolling out self-directed support and personalization policies in health and social care which follow from the direct payments developed by disabled people and their organisations to ensure service users choice and control in their lives and support services, support which highlights the social as well as the personal. I want to stress the philosophical change, while acknowledging how far the practical reality still has to go. But crucially what we can see here, informed by the emancipatory disability research developed by the disabled people's movement is the

reframing and reconceptualisation of issues and experience formerly medicalised, in terms of autonomy, self-determination and a social understanding. What was a narrowly health agenda, now is recognized to be significantly a social and support one, which also requires equal access and inclusion to all mainstream services, from education and employment, to training, planning and recreation.

I have tried in my comments, using three examples, to show the value and importance of engaging the experience, knowledge and research of service users and their organisations if we are to explore social care and social work research for the health agenda and indeed explore the inter-relations of the two social care and health. What I think we learn from this focus is the larger role that the social has to play in health and the problems there have been from the artificial separation of health and social care/support and the subordination of the latter. This focus helps us to see that social work, social care and health are not separate, even though too often treated as if they were. That there is more to do to reframe their balance and to address their complex inter-relations.

At the same time, I think if we are to take forward this helpful interest in service user knowledge and involvement in research and continue to gain the theoretical, research, policy and practice insights it can offer, then we must address some barriers that continue to operate. These include:

First, the continuing dominance of traditional positivist research approaches and related approaches, like randomized control trials – RCTs – and their prioritization as the ‘gold standard’ of research. A much wider range of research approaches must be supported, including user controlled research as a helpful element in the overall spectrum of research approaches. We know that at present user knowledge and research face prejudice and are still often devalued – in social work, it should be said, as well as in health research;

Second, government must take more seriously its commitment, first expressed in Increasing the Life Chances of Disabled People and now reinforced in its Independent Living Strategy to provide adequate and reliable support for a network of local user controlled organisations. We know these provide the essential base for effective user involvement, user involvement in research and user controlled research;

Finally, if we are serious about supporting user involvement, then to challenge rather than mirror existing barriers and exclusions, we must make it more possible for the diversity of service users to be involved in the co-production and reform of policy, practice and of course, research. We now know much more about the barriers associated with and working on, what are called ‘seldom heard voices’ and ‘the hard to reach’ and work like the projects of SCIE and Shaping Our Lives to explore their exclusion and enable their inclusion give us much more evidence about how to engage them more equally. Effect policies and practices for access and inclusion need to be developed

to make this possible. Here we have tools to make real, government commitments to and enthusiasm for user involvement in policy and research. These involvements, we know, help give new priority to the social perspectives in health and health research that we have brought us together today. Thank you.

## **References**

Beresford, P. Adshead, L. and Croft, S. (2007), *Palliative Care, Social Work And Service Users: Making life possible*, London, Jessica Kingsley.