

It is time that service users played a bigger role in mental health research

the bigger picture

Nick Hervey is head of social care, Southwark Integrated Adult Mental Health Service, and a member of the Social Perspectives Network (SPN) executive committee

For information about SPN, visit www.spn.org.uk

Research is generally perceived as an activity pursued by a minority of the population, in the rarified atmosphere of universities and hospitals. It is mostly seen as an activity for people with advanced academic qualifications who are somewhat removed from the rest of us. All of which raises the question, is user involvement in research really possible?

Traditional discourses about the research process have taken little account of the views of service users either as subjects of research or as potential contributors to the process. Recently this has begun to change in the mental health arena with the growth of a number of groups and initiatives. Unfortunately, these developments have come at a time when the government's re-organisation of research funding means that money available for smaller scale research has largely dried up. This is a fundamental problem where there are still unresolved conflicts about the locus of control/ ownership in research, leading to dislocation and fractious endings, as was seen recently with the concerted resignation of the members of SURGE, the user research arm of the Mental Health Research Network (MHRN).

There are fundamental differences of opinion about the validity of different research approaches, with most funders emphasising the randomised controlled trial (RCT) as the gold standard for scientific research. There are, however, a number of other equally valid methodologies. Many non-medically based professionals have spent years tussling with the complexities of evolving a shared core of values and practice – which can be seen reflected in the admirable Values and Methodologies report produced by the Social Perspectives Network (SPN) in 2006. We believe that rigorous and transparent qualitative research has a crucial part to play. Mental health research goes beyond the clinical sphere and investigations should therefore not be restricted to the narrow methodology of the RCT.

The resignation of SURGE members in 2007 has led to a debate about how user involvement in research can be enhanced nationally. The MHRN exists to support large-scale research projects that aim to make break-through advances in mental health care. While we respect the hard work of the MHRN in supporting user involvement, the perspectives and views of those with personal experience of mental ill-health need to be given a more equal status. This implies some sharing of

power and a recognition of the validity of different forms of knowledge. Recent experience of user involvement has also led to the elucidation of a set of principles within a growing body of literature, including significant contributions from Dr Jan Wallcraft and Professor Peter Beresford. We see user involvement as fundamental to the delivery of ethically sound mental health research. That involvement has to extend beyond consultation to full engagement in deciding the topic, framing the research question, shaping the methods of research, interpreting the findings and dissemination. It is not an optional add-on.

In 2006 and 2007 the South London hub of the MHRN ran conferences showcasing user involvement in research. It has since been working with service user focus groups to develop a set of pathways into research for service users. This involves identifying a menu of opportunities, linked with the training necessary to take advantage of them. Meanwhile, some members of the Network's central hub have been looking at an alternative strategy – identifying people who have become ill while going through tertiary education and recruiting them as researchers, on the basis that they may already have certain academic attributes deemed necessary. Although an attractive shortcut to increasing the number of users involved in research, this seems to miss the point. We need to involve a much wider group of service users who have an intrinsic stake in how mental health research develops. The South London hub's menu of opportunities will allow service users to become involved at different levels and progress from one level of activity to another.

SPN currently hosts the original NIMHE/SCIE social care mental health research forum, which merged with its own research group in 2005. This draws together user and practitioner researchers as well as academics. We welcome the MHRN's plan to recruit graduates with experience of mental health problems to the network, but we believe it is also vital that other pathways are developed to support the skills development and involvement of non-academically trained service users. SPN, in partnership with Shaping Our Lives, has recently won a tender from INVOLVE to analyse examples of user-controlled research. Vicky Nicholls, SPN's joint project co-ordinator, will be leading this, which will be an important step in establishing a database to showcase examples of user-led research. ■