

How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study

Diana Rose,^{1*} Marian Barnes,² Mike Crawford,³
Edward Omeni,¹ Dee MacDonald² and Aaron Wilson¹

¹Service User Research Enterprise, Institute of Psychiatry, King's College London, London, UK

²School of Applied Social Science, University of Brighton, Brighton, UK

³Centre for Mental Health, Imperial College London, London, UK

*Corresponding author

Declared competing interests of authors: Diana Rose receives support from the Biomedical Research Centre for Mental Health at the South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, King's College London.

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published April 2014

DOI: 10.3310/hsdr02100

Scientific summary

The ENSUE study

Health Services and Delivery Research 2014; Vol. 2: No. 10

DOI: 10.3310/hsdr02100

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

The background to this report is the increasing policy emphasis on user involvement in health service planning and delivery, specifically in mental health, and theoretical frameworks concerned with organisational change and new social movements. The study comprises primary research following on from literature reviews conducted by two members of the research team. It has strong patient and public involvement.

Objectives

The following research questions were asked:

1. What have been the impacts of user involvement in mental health in terms of service development, delivery, commissioning and personal benefit to users? We have the same research question for front-line staff.
2. How do managers and other key decision-makers respond when user-led organisations (ULOs) approach them, seeking change?
3. Moving to a more individual level of user involvement, what is the role played by user governors on trust boards and how do key decision-makers on the boards respond to them?
4. What are the implications of the move to 'personalisation' in both health and social care, specifically in terms of the role of ULOs in brokerage and care planning?
5. What are the underlying assumptions, beliefs and values held by senior managers about the benefits and drawbacks of user involvement in mental health, and how do they individually and collectively respond to, facilitate or impede this?

Methods

The study took place in three UK NHS foundation trusts, two metropolitan and one rural. Quantitative methods, in the form of surveys of service users (SUs) and front-line staff, were used to answer research question 1. Service users were recruited from outpatient clinics and day centres, and front-line staff were sent an electronic survey via their human resources department. As part of this study of impact, semistructured interviews were also conducted with 24 senior members of staff. Research question 2 was approached using ethnographic and case study methods. We worked with six ULOs. They were asked to identify a goal that would involve them in interactions with managers and these interactions were observed, as were the meetings of the organisations themselves. Two members of each ULO kept reflective diaries. The ethnography lasted, on average, for 1 year. For research question 3, Council of Governor meetings were observed and, in one case, subcommittees of the Council were also observed. Focus groups were conducted with user governors and the chairperson of the Council of Governors (CofG) was interviewed. The aim was to find out how much influence the user governors had and whether or not this development represents a shift from more collective to more individual forms of involvement. For research question 4, we held focus groups with SUs who were in receipt of personal budgets, with the aim of finding out about their experience of the assessment process, how they spent money allocated and whether they did this at a collective ('pooled') or individual level. For research question 5, we convened a deliberative workshop of the senior staff interviewed in phase 1 and presented our main findings to them. The aim of the workshop was for them to help us interpret our findings from the perspective of key decision-makers.

Results

The survey of SUs showed that 'ordinary' users of mental health services did have some involvement in service planning and delivery. This marks a change from 20 years ago. Where SUs were involved, they overwhelmingly thought that this had a positive impact. Staff were also found to encourage service user involvement (SUI) in the planning and delivery of care. Younger staff, and those with a social work background, as opposed to a nursing professional background, were more likely to believe that involvement is having a positive impact. In free-text responses, both SUs and staff mentioned having a voice and shaping services, as well as empowerment, as positive benefits of user involvement. Disadvantages included tokenism and stress for both groups.

For all the qualitative work, which delved more deeply into user involvement activities, a major finding was the scale of change and complexity in organisations in which SUs and their organisations were trying to effect change. This impacted on staff, both front-line and senior, as well. The ULOs had to adapt to the changing and dynamic organisational context and this posed many challenges. One of the groups, which prized its autonomy and its campaigning stance, actually failed during the time of the ethnography and this seemed to be because it could neither comply with the behavioural norms of the current negotiating context nor ally itself with other user-focused organisations in a way that both commissioners and providers expected. Other ULOs adopted the strategy of both specialising – for example concentrating on one group of mental health SUs, focusing on creative activities or on evaluation and research – and complying much more with the corporate demands of behaviour, professionalism and language of key decision-makers and the mental health system. However, such success as they achieved was often partial or bought at a price. Thus, a research group had to function in the context of other stakeholders who valued grant income and publications over user involvement in their research, and the group representing an underserved population had to relinquish some control to a much larger voluntary organisation. A group that did try to intervene on a county-wide basis in the rural trust found itself struggling for representation in a provider forum as well as in conflict with the local Patient Advice and Liaison Service. This was not an isolated case. The group also experienced a considerable stretching of its resources.

The observations of, and focus groups with, user governors also showed the impact of organisational complexity and the demands of operating within the contemporary NHS. User governors had to adopt the language and behaviour of formal meetings otherwise they were deemed 'inappropriate'. There were variations between the trusts. One metropolitan trust had set up a complex series of subcommittees, one of which was chaired by a user governor, and here the institutional rules and norms were more relaxed. The participants in the focus group for this trust were positive about the influence they were able to exert. In the other metropolitan trust the participants were negative to the point of being angry and said that they were unclear about their roles and responsibilities. The research team had great difficulty gaining access to this CofG and to the user governors themselves, and it seemed that the trust had some distance to travel before user governors could become a real and effective part of the landscape. In the rural trust there was also some disquiet but also, towards the end of the observation period, some evidence that the user governors wanted to meet together and exert some collective influence. A further issue was that of representation, something that has beset SUI in mental health service planning and delivery since the outset and appears here in a new guise as a 'democratic' concept of representation rather than one based on typicality. Finally, we found that informal networking opportunities were just as important as formal meetings with respect to SU governors having an impact.

Personalisation and individual commissioning are government policy. Our intention had been to run two focus groups with people in receipt of personal budgets in each trust. This proved impossible. Recruitment was very difficult because it was hard to find anyone who was indeed in receipt of a personal budget. Those who came forward often were receiving other welfare benefits or even wanted to attend the focus group as a route to getting a personal budget. We were able to run only one focus group per trust and the discussions centred on the assessment process, how complex it is, and how the Fair Access to Care assessment is inappropriate to those with mental health needs. We held one group in an arts venue,

where individuals were pooling their budgets to 'buy' an arts class. Our research question included the place of ULOs as brokers for personal budgets, in place when we wrote our protocol, but these were not in evidence.

The deliberative workshop for senior staff generated three main issues. One was to do with the reconfiguration of mental health trusts, the provision of services outside the geographical area and the consequent rupture between service provision and locality-based user involvement activities. Second, it was noted that our focus on normative language was perhaps misplaced because 'management speak' is empty. At least, this has to be refined as there are contexts in which the voices of experience, or SUs' stories, are valued. Staff training is a case in point where it is helpful to hear about living with a mental health condition and the experience of receiving treatments and services. Finally, some senior staff were of the view that how user involvement is conducted should be left to SUs themselves and their organisations. It was pointed out that our findings concerning institutional rules and norms and organisational complexity mean that there is a context that defines what can and cannot be done, which is not in the control of either SUs or staff.

Conclusions

We conclude that the organisational change and complexity that has characterised the NHS and social care in recent decades, and which was heightened at the time of our research, has shifted what mental health SUs and their organisations are able to achieve. At the same time, SUI has become an integral part of the system. Old-style ULOs find it difficult to survive in this climate and, so, groups have adapted and mental health SUs have taken up new roles, for example as user governors. Our hypothesis that we are witnessing a shift from more collective to more individual forms of involvement needs to be refined, and is rendered more complex owing to evidence that mental health SUs are unwilling to give up a collective voice. However, this new social movement has certainly changed in the last 30 years. It has become an established part of the landscape but in the process has had to adapt. Managers and decision-makers need to attend to this new configuration in their interactions with SUs and their organisations.

Our main implication for health-care concerns personalisation and individual commissioning. This is hailed as a major transfer of power from state to citizen. However, what we found was confusion, bewilderment and fear that welfare benefits would be lost at the same time as valued services such as day centres were cut. We did, of course, look only at mental health SUs, and personalisation has been drawn in the image of support for people with physical and sensory impairments. More research in this area is urgently required.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: www.netscc.ac.uk/hsdr/

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 10/1008/09. The contractual start date was in March 2011. The final report began editorial review in May 2013 and was accepted for publication in October 2013. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2014. This work was produced by Rose *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Health Services and Delivery Research Editor-in-Chief

Professor Ray Fitzpatrick Professor of Public Health and Primary Care, University of Oxford, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Peter Davidson Director of NETSCC, HTA, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Professor Elaine McColl Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Professor of Health Sciences Research, Faculty of Education, University of Winchester, UK

Professor Jane Norman Professor of Maternal and Fetal Health, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professorial Research Associate, University College London, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk