Module:
Mental Health in the Community

Week 2
Current conceptualisations of mental health

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Lecture transcript

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It was recently noted that service users 'are working in a climate of organisational change and complexity that has forced them to adapt and change, such that traditional styles of confrontation and campaigning have given way to the adoption of more corporate and professional modes.' This suggests a broadly shifting political spectrum with consumerism and pragmatism notably tackling stigma, replacing more radical ideology, as both impetus and framework for user involvement.

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In an evaluation of studies adopted by the Mental Health Research Network, Kristina Staley found that although service users were included in 40 per cent of randomly selected projects, there remained great variation in the nature of their input and their overall impact. A lack of time and resources, and the absence of a shared, practical definition of 'service user involvement' were foremost amongst problems identified.

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In their 2002 analysis, Trivedi and Wykes subjected the process of user involvement to 10 questions, which arose in the development of a joint research project. Their answers are an amalgamation of the user and clinical researcher considerations and are affected by hindsight.

They found that the involvement of the user researcher changed the focus of the study in its design and content. More attention was paid to the intervention itself and the way in which it was delivered. This process increased the amount of time taken to carry out and write up the project, as well as incurring financial costs for user consultation payments and dissemination.

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All studies listed on the Mental Health Research Network portfolio database were interrogated using logistic regression, ANOVA, and Pearson's correlation to identify associations with study characteristics, funding bodies, and recruitment success. Results suggested that patient involvement increased over time, although in some areas of research, it remained limited.

Some funders, especially the National Institute for Healthcare Research, had more associated patient involvement than others. Studies that involved patients to a greater extent were more likely to have

achieved recruitment targets, defined as reaching at least 90 per cent of the target.

Other headline findings included: democracy and empowerment of service users, identification and prioritisation of relevant research topics, eliciting richer data because participants were more ready to share personal and perhaps stigmatising information, service user involvement required and recommended by increasing numbers of funders, the generation of representative and robust findings, and evidence that user involvement increases the likelihood of a study's success.

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User involvement can take different forms and mean different things to different people. It should be seen as a set of techniques, rather than a single approach. What works with one setting or population doesn't necessarily transfer to another context.

The above model demonstrates three different levels of involvement, ranging from consultation - the most superficial or short-term - to collaboration, to user control. While the latter, user-initiated approach is less common, new technologies and collectives are promoting developments in this field. For example, the creation of free online training resources for service users who want to do their own research or learn more about the research process has also contributed towards reducing the knowledge and power gap between researchers and participants.

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The SURE model, described above, remains highly unusual. More commonly, service user researchers will operate outside mainstream academia or organisations with collaborations more typically occurring on a project-specific, consultative basis. In these circumstances, expectations and objectives need to be agreed and clearly stated from the outset for the benefit of all involved.

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INVOLVE is an national advisory group that supports greater public involvement in NHS, public health, and social care research. It is funded by and part of the National Institutes of Health Research, and has around 30 members, including health and social care service users and practitioners, carers, people from voluntary organisations, managers, and researchers. It was created in 1996 to promote public involvement in NHS, public health, and social care research.

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Since 2005, details of involvement activity are required by funding bodies and NHS ethics committees. But this led critics, such as Peter Beresford to comment that 'recent interest in service user knowledge is part of broader pressure from funding bodies to increase user involvement.' Thus these views and ideas can be critiqued as merely another data source to inform and support a more traditional research design, rather than as a way of enhancing democracy and empowerment. For some people, this represents a move away from the more ideological basis of service user involvement.

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A further current concern is that amidst growing pressure of service user involvement in research, the names and views of certain populations are liable to be overlooked or neglected. Thus '"user" or "public/patient involvement" has become a shared goal across all shades of politicians and policy makers. However, we know that some groups, particularly from minorities, often experience generally inferior access to support and services. The same groups are likely to have inferior opportunities to get involved in schemes to strengthen their voice. The combined effect of these two factors is likely to be to exacerbate and perpetuate inequalities faced by some of the most disadvantaged groups in our society.'

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Peter Beresford makes the following recommendations for challenging this imbalance: first, ongoing review and evaluation of organisational policies, processes, procedures, and practices, including who is being included and excluded; an organisational commitment to and training in equality of opportunities; specific strategies for involving excluded groups and imaginative ways of working together; clarity on the issue of representation, i.e. who is speaking for whom - this is of particular importance when engaging with minority groups within minority groups, e.g. BME people with experience of mental distress; and finally, evaluation of participation to assess how inclusive and diverse it is.