

# Module: Mental Health in the Community

## Week 2

### Current conceptualisations of mental health

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#### Topic 2

#### 'Nothing about me without me': The growth of the expert by experience

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#### Lecture transcript

##### Slide 3

The critical position of seeing psychiatric hospitals and the discipline itself as fundamentally coercive appears to underpin the social and cultural shift that occurred in the 1960s. Some factions desired more dramatic changes to mental health care than what were already underway, with a rare convergence of left and right wing support for asylum closure. Left-wing authors depicted psychiatry as one manifestation of the controlling arm of the bourgeoisie. For feminists, it became emblematic of more general patriarchal power and gender inequalities.

##### Slide 4

Sociologist Erving Goffman proposed that the total institution actually aggravated long-term difficulties of people by fostering dependency, routine, and isolation from normal, everyday life. In *Madness and Civilization*, Michel Foucault argued that mental illness was an 18th century social construct, depicting institutions as tools of oppression and depersonalisation, their staff as agents of social control.

Furthermore, libertarian psychiatrist Thomas Szasz denied the very existence of mental illness, viewing psychiatric disorders as the product of medical misinterpretations imposed on social deviance, whilst Ken Kasey's *One Flew over the Cuckoo's Nest* also conceptualised psychiatric patients as nonconformists. Within Britain, the work of R.D. Laing gained particular prominence, rejecting medical psychiatry and encouraging greater attention to patients' lived experiences.

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The 1960s have been regarded as the critical decade in British psychiatry, with radical overhauls of existing health policy and services organisation. In his Water Tower speech of 1961, Minister of Health Enoch Powell called for large scale asylum closure in favour of community-based services, demands based reportedly on declining long-stay mental hospital populations. This rousing address foreshadowed the National Hospital Plan of 1962, within which psychiatry was to become a core speciality a new district general hospitals, and mental hospital provision halved.

Other motives ascribed to this policy include a desired convergence with general medicine, therapeutic optimism, and a comparison with pioneering general hospital units. Furthermore, antipsychiatry works of the 1960s and '70s popularised the notion of insanity as a social construct, problematised by medicine, politics, and law, views which gathered support from both inside and

outside of the psychiatric profession. Biological and social constructionist views on the origins of mental illness were similarly invoked as justification for spending cuts and asylum closure.

### Slide 6

This is Colney Hatch Lunatic Asylum, originally built on the land outside North London. Gradually, the city encroached and it became part of the suburb. At its height, in the mid 1950s, it accommodated over 2,000 people. It was renamed Friern Hospital in the 20th century. This is how people with mental health problems were treated for nearly 200 years. Another example, Bethlem Royal Hospital, is Britain's oldest psychiatric institution, founded as a priory in 1247. Today, it is part of the South London and Maudsley NHS Foundation Trust.

The alleged disorder and neglect associated with its Bedlam alter ego has sustained public and academic interest, yet less work has been undertaken hitherto on Bethlem's recent history, including the ascent of new ideas and approaches in the lives of people connected to the hospital. By contrast, a recent project, 'Mansion in the Orchard,' actively involved current and former service users, staff, and local residents throughout all stages of creating and disseminating a public history of the hospital.

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In practice, mental hospital closure was a more gradual process. Introducing the 1975 white paper, 'Better Services for the Mentally Ill,' Labour Secretary of State, Barbara Castle, conceded the shortcomings of the Hospital Plan, cautiously noting the limited scope for progress within the near future, and voicing concern over the running down of mental hospitals before community-based alternatives were available. Peter Barham described the inability of community care to deal with the vicissitudes of mental illness. He implicated these failures in increasing the stigma and isolation experienced by recently discharged patients and creating generations of new long-stay and revolving door patients.

### Slide 8

Although traditional psychiatric hospitals continue to play an important role in mental health care, late 20th century decarceration also provided momentum for a new generation of community-based studies, patient-authored accounts, and activism. Apart from the work of Viv Lindow in Bristol, the first piece of research was a collaboration between Camden Mental Health Consortium and a voluntary organisation called Good Practices in Mental Health.

The project was about service users' views of the new inpatient provision in a district general hospital that had replaced Friern. Two user controlled research projects, Strategies for Living, and User Focused Monitoring, began in London in the 1990s. Strategies for Living was based in the Mental Health Foundation and looked at peoples' own strategies for dealing with mental distress alongside of, or instead of, statutory services. The coordinator was a service user and so were all of the interviewers.

The other project was a peer evaluation of community and hospital services and was focused on specific localities. Again, the coordinator was a service user who provided research skills training to local service users. Both these projects published reports in the year 2000. The service users who lead this research were members of the service user movement and took their questions and sometimes their methods from it. They were openly political, which some critics understood as biased.

Peer review of hospital and community mental health services later spread to other locations and services, assisted by the work of INVOLVE, which is a government funded national advisory group on public involvement in research.

## Slide 9

The 2001 creation of the Service User Research Enterprise, SURE, marked the transition of user-led research into academia and emerged from the efforts of its first director, Professor Dame Til Wykes, to champion service user involvement in all aspects of research. SURE conducts research that tests the effectiveness of services and treatments from the perspectives of people with mental health problems on their carers. It is based on the premise that service user researchers have the advantage of insider knowledge about mental distress, treatments, and services, in addition to conventional academic training and qualifications. These different truths can represent a contrast to accepted psychiatric wisdom and hierarchies of evidence. SURE is the largest academic department of its kind in the world. The following groups are also prominent within the wider research community.

## Slide 10

SURE Search was established in 2001 as a non-affiliated organisation based at the University of Birmingham. Members include users and survivors of mental health services and their allies who have experienced or an interest in mental health research and education. Shaping our Lives National User Network is an independent user-controlled group, think tank, and network. It began as a research and development project, gaining organisational independence in 2002 and working with a wide and diverse range of service users.

The Survivors History Group was founded in April 2005 to value and celebrate the historical contributions of mental health service users. It preserves historical material, maintains a detailed online mental health timeline, and holds group meetings every two months in London to discuss issues of both historical and contemporary relevance. The McPin Foundation was established in 2007, initially focused on promoting mental wellbeing by awarding grants, evolving into a dedicated user-focused mental health research organisation from 2012. It now employs core staff and a bank of peer researchers for contracted projects.

St Georges University of London emphasises peer support working and co-production approaches, working alongside researchers with lived experience of mental health problems to critique and strengthen the production of knowledge about mental health. Internationally, there are many individuals working as service user researchers, but more often than not, they are the sole person in a department within that remit. Lone working also happens in England and the devolved nations.

Until recently, the theoretical and methodological status of these projects and units was either mainly descriptive or constituted a rather simplistic critique of the medical model. However, from the late 1990s onwards, edited collections have started to appear, which offer more sociological critiques of conventional mental health research or draw on epistemologies derived from feminism and postcolonial studies. In this way, they reframe the double identity of researcher and mental health service user as one of a specialist knowledge broker.

## Slide 11

A range of organisations and individuals have become engaged in mental health service user, or survivor research, on a national and international scale. These have varied theoretical agendas, aims, and methods, as Jasna Russo's quote indicates.

“‘Service user,’ in Europe, or ‘consumer’ in Australia, New Zealand, and USA, on the one hand, and ‘survivor of psychiatry’ on the other, are expressions of two different perspectives on psychiatry. The first one focuses on reforming the existing system, while the second, puts the entire psychiatric system in question, including the very premise of mental illness.’

It is crucially important to distinguish ‘user involvement in research’ from ‘patient participation in clinical care and planning’. This lecture is concerned with the former. These are separate but related identities a person can have, and ‘service user researcher’, ‘peer researcher’, or even ‘expert by experience’ should never be regarded as interchangeable with ‘patient’ or ‘client’. Nevertheless, role

blurring and misconceptions continue to present a challenge to successful collaboration and co-production of research.

## Slide 12

The term 'service user' itself, whilst widely used, has also attracted criticism from groups such as Shaping our Lives for being value laden and sometimes restrictive with its implications of passivity and its seeming disregard for other aspects of an individual's identity. The label also fails to capture those who may qualify for services but are, for various reasons, unable or unwilling to access the support. These considerations are of increasing importance amid widespread cutbacks to NHS mental health provision.

There are further debates regarding the recency and specificity of the user experience informing research. Hugh McLaughlin describes three types of service users researcher: direct, indirect, or alternative. The first category refers to those with recent or current experience of mental health services from the service provider conducting the research. Yet, there is no working definition of recency, and is it possible or ethical to impose deadlines on how long someone can call themselves a service user researcher?

Indirect service user researchers could typically be involved in studies focused on related services outside their geographical area, e.g. as part of a national or multi-site project, and thus possess similar, if not exact knowledge of the services under investigation.

Finally, the alternative researcher has experience of using services in one specific domain, e.g. breast cancer, and may contribute to general panels on health and welfare issues. The latter approach is increasingly controversial for its assumed similarity and generalisability of service user experience.

## Slide 13

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, and what works with one setting or population, doesn't necessarily transfer to another context. As just one example of user-led research, the service user research enterprise at the Institute of Psychiatry, Psychology and Neuroscience tests the effectiveness of treatments and services from the perspective of people with mental health problems and their carers. It seeks to involve service users in a collaborative way in the whole research process, from design to data collection, through to data analysis and dissemination of results.

SURE is also unique in having a collaborative management structure, comprising one conventional university researcher and one user researcher. Elsewhere, user involvement in mental health services has evolved in response to shifts in institutional cultures. A briefing paper from the NHS Service Delivery and Organisation R&D programme is based on the findings of two literature reviews, one carried out by SURE and the other by Imperial College London. SURE's review investigated user and care involvement in managing organisational change within mental health services, examining how users and carers have been consulted and the best way of involving them.

SURE's innovative user-focused remit has generated influential studies and shaped national treatment guidelines. This is included pioneering user-led evaluation of cognitive remediation therapy, CRT, which highlighted key therapeutic problems, notably threats to self-esteem from negative feedback and contributed directly to service refinement. SURE were also the first to systematically review patient opinion about electroconvulsive therapy, ECT. By highlighting the significance of post-treatment memory loss, this study challenged official estimates of patient satisfaction with ECT.

In 2011 to 2012, Professor Rose co-chaired the NICE guidelines on the service user experience in adult mental health services. Dame Professor Til Wykes also leads the patient and carer involvement theme in the NIHR Biomedical Research Centre for Mental Health.

## Slide 14

Translational research aims to convert findings from basic research more quickly and efficiently into clinical and health care practice. The translational pathway was initially understood as unidirectional, moving from the laboratory to the clinic. But researchers and policymakers increasingly argue that the commonly used phrase 'bench to bedside' oversimplifies what is actually a complex and two-way process. There is therefore growing recognition that knowledge from the bedside must feed back into the laboratory if the translational endeavour is to have a real and lasting success.

Service user generated or grounded knowledge can thus help to bridge the translational gap of clinical or academic research and improve organisational efficiency through the easier implementation of findings. These first-hand experiences may also be invested in evaluating and enhancing the validity of outcome measures, thereby highlighting areas of concern to service users or assessing the acceptability and feasibility of proposed changes to treatments or services.

## Slide 15

A number of key approaches are now explored in the context of a consumer study of ECT. Patient-centred systematic reviews are an adapted method of systematic reviews to make it more user-focused. For a study exploring consumer's perspectives on ECT, the two main researchers had experienced ECT, i.e. they had inside knowledge. Evidence collected included peer reviewed literature as normal and systematic reviews, but also grey literature and qualitative data, including testimonies sourced from a video archive on the internet.

Many people who had ECT complained of long-term retrograde memory loss. In England, people must sign a consent form before ECT is administered. Researchers were concerned to see whether this consent was freely given. Conventional research showed much higher levels of satisfaction with ECT than this user research. There was no overlap in the estimate of benefit between the two groups. New NICE guidelines on ECT developed as our research was being conducted, suggesting an influence of consumer review, especially around information and consent, including risk of memory loss.

User research can therefore have a direct effect on national policy. Patient-reported outcome measures, PROMS, and patient-generated patient-reported outcome measures, PG PROMS. In the last few years, there has been a move to patient reported outcome measures. These are merely filled in by patients. SURE's method is to generate PROMS entirely from the user perspective to reflect their views and priorities.

Examples have included discussing medication side effects and experiences of inpatient care. The method used is participatory research, which aims to reduce the power imbalance in the research process. The researchers are also service users, and so share something with the participants in the research, although this does not have to be an exact match.

A method called a 'discrete choice experiment' involves choosing the so-called least worst side effects, can inform drug developers of key side effects to avoid from the service user perspective. The following processes may also be required in developing and refining a new measure or questionnaire that it can be applied in other contexts.

Focus groups can be conducted on a variety of topics and at different stages of the research process. This can also be hypothetical debate or on issues of more immediate concern to their care. A focus group typically comprises six to eight people with one facilitator with experience of inpatient care and also another service user. The group may meet twice to make sure we accurately capture their views and we'll be reimbursed for their contributions.

The conversation is recorded with participants' consent and a thematic analysis is conducted, typically using NVivo software. Expert panels - one drawn from focus group members and one independent (participants had also been inpatients within the previous two years) - they're tasked

with amending and refining a measure and making sure that the language and layout are appropriate and consistent with what they wanted. Usually, there are quite a few changes made at this stage.

A feasibility study-- the purpose of a feasibility study is to make sure that a new measure is easy to complete, it's given to participants in groups of approximately 10, and iteratively refined until all respondents find it easy to complete. In some cases, the participants are actually in a hospital. For example, inpatient care - there was much anecdotal evidence and grey literature suggesting that ECT was profoundly disliked by service users. The previous study took a more rigorous approach to exploring this issue.

This finally became the main outcome measure in an RCT, evaluating the introduction of psychological therapies on acute wards. The research was collaborative, but SURE's part was user-led. The measure is called VOICE, which stands for Views of Inpatient Care. Participants in focus groups had been inpatients in the local NHS Trust within the previous two years. There was a specific group of people who had been detained i.e. sectioned, although all groups actually included formally admitted patients.

### **Slide 16**

The marginalisation of experiential knowledge pervaded other sectors, notably disability, to an emphasis on deficit and pathology served to justify the segregation and institutionalisation of the ill or impaired. Thus, service user testimony, which additionally devalued or omitted from psychiatric knowledge production, with a focus instead on assumptions and interpretations of these experiences and views. Historically, there would seem to be a special way in which the mad were excluded from knowledge.

Michel Foucault argued that with the Enlightenment, the privileging of reason and the birth of science, positioned the mad as the embodiment of unreason, unwilling or unable to become the docile bodies required for labour in the Industrial Revolution. If the epitome of knowledge is reason, then so-called "mad knowledge" is an oxymoron. It is likely that methodologies will change and certainly most service user researchers draw something from participatory forms of research.

There is a suggestion, often implicitly, that user research is biased, anecdotal, and carried out by people who are overinvolved. All research comes from a certain standpoint. Conventional researchers think that what they do is obvious. Nothing is obvious. But service user researchers are often more explicit about these inherent biases than mainstream researchers.

### **Slide 17**

Diane Rose posits that some opposition stems from the challenge user-led research represents to conventional hierarchies of status and knowledge. Most of the projects SURE have been involved with are collaborative, and nearly always headed up by professors of psychiatry or psychology. Rose states this is not just status or power, although that exists, but a more subtle undermining of user-produced knowledge, e.g. 'Are you a researcher, or are you a patient?' or, 'I wonder what your diagnosis is then.'

Furthermore, within ostensibly collaborative research, service user researchers may be, albeit often inadvertently, denied access to the training and resources enjoyed by other team members, and may be excluded from key discussions or the dissemination of results. Such disadvantages are commonly due to deficiencies in research design and recommendations for successful user participation are discussed later in this lecture.

### **Slide 18**

Hierarchies of evidence: evidence-based medicine hierarchies rank study types based on the strength and precision of their research methods. There are different hierarchies for different question types, and even experts may disagree on the exact rank of information in the evidence

hierarchies. Still, it is generally agreed that current well-designed systematic reviews and meta-analyses are at the top of the pyramid and that lay expert opinion and anecdotal evidence are at the bottom.

The Cochrane Collaboration is an international voluntary organisation that prepares, maintains, and promotes systematic reviews of the effects of health care.

### **Slide 19**

The recovery model was developed by service users in the UK and the USA who wanted to avoid often damaging side effects of psychiatric drugs and to assume great self-management of their condition. It was originally seen as the antithesis of the medical model, and drew criticism from psychiatrists as being dangerous and irresponsible.

Yet this approach has more recently been integrated into mental health care. However, such professional interest in the recovery model has also prompted complaints from some service users that it has been hijacked from its original routes and aims, with its goals modernised to an unhelpful and sometimes unrealistic extent. For example, the ideals of service users, managing complex tasks unaided or finding employment have been regarded as unattainable for some people. In endorsing a model of individual responsibility, it may appear to justify the reduction or closure of services.