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# Research, recovery and mental health: challenges and opportunities

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## *Introduction*

Efforts to demonstrate the validity and effectiveness of interventions in mental health have historically used traditional research paradigms. The development of such paradigms has predominately involved academics and health professionals, commonly with limited to no involvement of those who avail of the interventions and those who support them (e.g. family members). The Recovery movement in mental health has, in contrast, highlighted the importance and value of developing partnerships, at all levels of service provision, between those who provide and those who use mental health services. The nature of the research undertaken in the mental health disciplines, its interpretation and its use, may benefit from an examination from this perspective.

## *The Traditional Research Paradigm in Mental Health*

The traditional research paradigm utilised by the mental health disciplines (nursing, psychology, psychiatry, occupational therapy, social work) is centred on positivist values such as objectivity, neutrality and distance, with the aim of achieving a rigorous and scientific methodology. This paradigm views meta-analyses, systematic reviews and randomised control trials as the ‘gold standard’ of research evidence. This view continues to dominate within the field (Cohen, Stavri & Hersh, 2004; Glasby & Beresford, 2006) and is the basis for many government guidelines on mental health, including those produced by the National Institute for Health and Clinical Excellence (NICE, 2005).

The adoption of this positivist approach has traditionally led to limited involvement of individuals who avail of mental health services, and those who support them, in the research process. Such involvement is commonly believed to introduce ‘subjectivity’ and ‘bias’. Therefore, the involvement of service users in research is typically restricted to the role of

passive participant, the explicit aim of such studies being to observe the effects of particular interventions on those outcome variables deemed important by the researchers. These studies are then 'peer-reviewed' by other researchers and published in journals for the academic community. This community, and this process, is commonly devoid of membership from individuals who use mental health services and those who support them. This traditional process runs the risk consequently of overlooking the unique and invaluable experience, knowledge and perspectives that service users can offer to research.

An additional argument originating within the human rights domain, advocates that service users are emancipated individuals with the right to have a fully-informed opinion on, and input into, processes which affect them, including clinical research. From this perspective, involvement only as a passive participation (e.g. as subjects in a clinical trial) departs significantly from the collaborative inclusive process that all citizens should expect from processes that could have real significance to the wellbeing of their bodies and minds.

The need to explore additional and alternative approaches to undertaking clinical research may also be prompted by the observation of certain researchers that there does not appear to have been any substantial improvements in outcome for individuals diagnosed with mental health disorders over many decades (cf: Timimi, 2014 for a review of the longitudinal evidence). Slade, Amering and Oades (2008) reviewed 9 studies assessing long-term outcome in schizophrenia over twenty-five years and observed recovery rates ranging from 46% in 1979 (Tsuang, Woolson & Flemming, 1979) to 62-68% in 1987 (Harding et al., 1987), with the most recent of the studies reporting a recovery rate of 56% (Harrison et al., 2001). The results indicated variable to no substantial improvement in outcome, despite several decades of research. This research appears to indicate that the traditional research paradigm commonly used by the mental health disciplines is producing results which are less optimal than originally hoped. In the search for more effective ways of understanding 'what works' in alleviating mental distress, a research process which has greater room for the voice of the service user may have the potential to lead to ways of working together which may produce better outcomes.

### ***The Recovery Movement***

Recently in Ireland, there has been a growing interest in involving individuals who have experienced mental illness in the development of mental health services, as experts

through experience. This may be seen as part of a wider international service user initiative known as the “Recovery movement”, which sees recovery from mental illness as a personal journey which involves fostering hope and identity, and achieving a meaningful life despite the limitations caused by illness (Anthony, 1993). The Recovery movement advocates for genuine equal partnership between the users of mental health services and those who provide them, at all levels of service provision. This may occur through measures such as collaboratively drafted individualised self-management plans, peer-support, co-produced policy, and through service user-led services. Such ideas have become increasingly influential in the development of government policy and mental health services worldwide. In England the NHS has committed to involving service users as active participants in treatment decisions, which is echoed in the rhetoric “No decision about me, without me” (Department of Health, 2010; 2012). The key strategy document for mental health services in Ireland, ‘A Vision for Change’ (Government of Ireland, 2006), proposes a person-centred treatment approach, with special focus on involving service users and their carers at every level of service provision e.g. “A recovery orientation should inform every aspect of service delivery and service users should be partners in their own care.” (Vision for Change, Executive Summary, pg. 9).

While it appears that the Recovery movement is impacting on policy and guiding service provision in many countries, this influence is not yet as apparent in the realm of research. A growing body of evidence outlining the benefits of recovery-oriented practice has emerged from the use of traditional research methodologies (cf. review from Slade et al, 2014). However, the incorporation of key recovery principles, such as co-production, in the carrying out of research itself remains in its infancy in many of the mental health disciplines.

### ***Research Models which Incorporate Recovery Principles***

There are number of research models that currently exist which embody many of the Recovery principles. For example, models of co-produced research have grown substantially in the field of social work in recent years (Beresford & Croft, 2012). Hanley and colleagues (2004) help describe the continuum of co-produced research which has three levels of service user involvement; user-involved, user-collaboration and user-controlled. User-involved research generally includes some consultation of service users, while user-collaboration research involves service users to a greater degree in tasks such as establishing the research

question, collecting and analysing data, and writing up the final report. As the name suggests, user-controlled research is concerned with carrying out research that service users are in command of, in which their views and experiences are paramount and the relationship between the service users and researcher is equal (Beresford & Croft, 2012). A Recovery-oriented research process would embody many of these principles, whereby service users are considered as active research *partners*, rather than passive research *participants*.

‘Action Research’ is another model that shares many of the same values as that of the Recovery movement. Action Research aims to bring about positive change for service users, through collaborative research studies which place equal value on the experience and expertise of the traditional researcher and the participant or service user, who work together as co-researchers in undertaking studies. The findings are then shared with all relevant stakeholders in an attempt to help researchers and participants jointly learn and further their understanding of a phenomenon (Kagan, Burton & Siddiquee, 2008). Recovery-oriented research would adopt a similar stance where the ultimate aim is positive change and increased understanding for both researchers and service users, as opposed to the more traditional objective of simply adding to the pool of knowledge among professionals. This could help bridge the often significant translational gap between clinical research being carried out and meaningful change occurring in frontline service provision.

It is worth noting that many public initiatives in the UK support involving service users who have personal experience of mental illness, or engagement with mental health services, as active contributors to planning, undertaking, and disseminating research, such as the Strategies for Living projects (Faulkner & Layzell, 2000; Mental Health Foundation, 2003), User Focussed Monitoring (UFM) at the Sainsbury Centre for Mental Health, and the Service Users Research Group for England (SURGE) supported by the National Institute for Mental Health England (NIMHE).

### ***Embedding Recovery Principles into the Research Process: A Proposed Framework***

Ultimately a Recovery-oriented research process would need to embed the Recovery principles of inclusion and partnership in the entirety of the research process.

***Formulating Research Questions:*** A partnership approach would begin at the very first stage of the research process, i.e. the development of the research question. By using a

panel of people affected by the issue under investigation, service users would help to generate research questions, and could assess the relevance of questions developed by professionals. This process would help to ensure that the issue is of real importance to service users and those who care for them, rather than being determined by researchers with potentially little to no lived experience of this difficulty.

**Research Design:** In the research design stage, service users would assist in identifying and defining variables, and the way in which they are measured, to ensure that the design is informed by the insights of those who have experienced the phenomenon first-hand. They would also help the researchers to identify practical issues which may lead to low participation and completion rates (e.g. asking people with low levels of concentration to complete long batteries of tests), which can easily be overlooked by researchers who do not share these difficulties.

**Ethical Approval:** Service users would also be involved in the ethics process, by sitting on ethics panels and by consulting on the guidelines and the criteria which must be met in order for approval to be granted. Service users and their carers could help to provide insight on issues of consent and capacity, and in developing information sheets and other communication to ensure they are written in a way which is easily accessible to potential participants.

**Recruitment:** Service users could also help with recruiting participants and conducting the study. Ennis and Waykes (2013) carried out a longitudinal investigation into service user involvement in clinical research, and found that higher levels of recruitment success were achieved in studies which had the greatest levels of service user involvement. Their investigation also points out the usefulness of training service users as interviewers for the data collection stage, as participants often feel more comfortable opening up to somebody with a shared experience (Ennis & Waykes, 2013).

**Dissemination and Impact of Results:** Service users would also be included in dissemination of the research, by including them in the 'peer-review' process and assessing the relevance of the study and the way in which it was carried out. Service user feedback could be published as a concluding section in all research papers or as a companion publication. Finally the concept of 'impact' could be reconsidered as the effect the research has had on the lives of service users (both those directly involved the research as those benefiting from service reform) rather than exclusively a judgement made by research 'peers' based on how many academic citations the paper receives.

## ***Challenges***

Changing the traditionally passive role of the service user in clinical research to a more active research partner could lead to a more Recovery-oriented process where the rights of the service user are more appropriately respected and where some of the limitations of the traditional research paradigm are overcome. However, there are some potential barriers to this approach which may need to be considered in order for Recovery-oriented research to develop successfully. Involving service users in research from a Recovery perspective needs to be a genuine effort. Tokenistic service user involvement, where service users are included to tick a box on an application form, or are only given menial jobs, needs to be avoided (see Staddon, 2015). Some of the key issues in this regard may include:

***Capacity and Respect:*** Processes which actively involve users of mental health services need to begin from a position of respect and acknowledge that power differentials between service providers and users bring with them the potential for abuse. This may be particularly the case where successful research may disproportionately benefit the mental health professional (e.g. by bringing professional kudos). Involvement of a range of service users, carers and other professionals, along with effective ethical processes, may attenuate to some degree the risk of exploitation occurring.

***Quality Standards:*** It is also important that Recovery-oriented research is carried out to a high standard in order to be considered credible. To achieve this training would need to be provided to both service users and service providers. This could also help to ensure that all service users are given an equal opportunity to become involved despite any previous lack of experience. Researchers will also need further training to help them develop new skill sets which enable them to work with service users in this way. In 2004, INVOLVE, a Department of Health funded initiative which aims to promote public involvement in NHS health care research, commissioned the TRUE project where training guidelines for researchers and service users interested in co-produced research were developed (Lockley et al., 2004).

***Logistical Barriers:*** A sufficiently wide pool of service users and family members/carers will need to be established to ensure research centres are not continuously using the same service user consultants. Service users will also need to be compensated for their time and therefore research participation may need to be included in the criteria being

established (cf: HSE, 2011 national guidance on reimbursement) for the reimbursement of service users working with statutory providers and academic institutions.

**Access to Publication:** Issues with credibility and access to publication are common in the domain of service user controlled research and this can lead to inferior access to funding and publication opportunities (Beresford & Croft, 2012). These issues may well be strongly associated with the continued dominance of traditional stances towards clinical research. Adopting a Recovery-oriented approach to research may require a broader cultural shift amongst academic, research centres and publication organisations on how we consider the purpose of research and how we assess the issues of quality and relevance in this domain.

### **Conclusion**

Traditionally, the mental health disciplines have utilised the dominant professional-led research paradigm to demonstrate the value of their work. Similarly, recent innovative Recovery-oriented practices have attempted to establish their effectiveness and credibility by applying the dominant pre-existing research paradigm. However, with the growing momentum behind the Recovery movement, increasingly the paradigm itself is being challenged (e.g. Cohen, Stavri & Hersh, 2004; Glasby & Beresford 2006). Consequently, the Recovery movement is more assertively setting out the benefits of a Recovery-oriented approach and questioning the value, to date, of the traditional research paradigm in mental health. A research paradigm which, in contrast, embodies Recovery principles would prioritise service users' own concerns and agendas, and assign to them equal importance as to that assigned to scientific rigour (as traditionally understood). The gains that could arise from empowering service users in this process and utilising their insights would be ones that benefited both researchers and service users. If the mental health disciplines are to remain faithful to their explicit aim of working collaboratively with service users, and continuously striving to better meet their needs, then the very research paradigm underpinning the work of these disciplines may need to evolve to incorporate the learning that service users alone can provide.

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