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## EDITORIAL

# The mental health strategy for Europe: Why service user leadership in research is indispensable

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### Abstract

Recent European mental health strategies and programmes declare service user involvement to be essential in the development and evaluation of policy and services. In light of the announcement in March 2011 by the World Health Organization Regional Office for Europe of a forthcoming new mental health strategy for Europe, we propose that service user leadership in research is the most effective way of enhancing such involvement and consider what is required to broaden initiatives across Europe.

**Keywords:** *views/attitudes of consumers, mental health policy, Europe, service user involvement in research*

In March 2011, WHO Europe announced the development of a new mental health strategy for Europe. There is clear commitment to including service users and families in the strategy's development (Muijen, 2011). Subsequently, there has been an announcement that there are four core strategic objectives of the strategy, one of which is that "people receive effective and respectful treatment – offered the way people want it" (World Health Organization Regional Office for Europe, 2011b). The announcement of the new strategy came on the heels of other European declarations, strategies and projects (Table I) that emphasise the indispensability of service user involvement in the development, implementation and evaluation of policies that relate to service users. In 2009, the European Parliament Resolution on Mental Health additionally called on Member States to empower organisations which represent people with mental health problems and their carers "in order to facilitate their participation ... in all stages of research into mental health". These declarations, strategies and projects emphasise that meaningful involvement of service users is central to their effective execution; they also indicate – whether explicitly or implicitly – that good policy is based on good research. We argue that "good research" in relation to these policy priorities is research that has involved service users (see also Faulkner & Thomas, 2002). If, for example, the forthcoming WHO Europe mental health strategy is to ensure that

Table I. European declarations, strategies and projects that emphasise service user involvement.

Date of adoption/ ratification, or time period of strategy or project	Declaration, convention, strategy or project	Specifications for service user involvement
December 2010	Ratification by the European Union of the UN Convention on the Rights of Persons with Disabilities (CRPD)	Articles 4 and 33 of the CRPD specify that persons with disabilities (this category includes mental health service users), and their representative organisations, shall be closely consulted and actively involved in the development and implementation of legislation and policies to implement the CRPD.
2010–2020	European Union Strategy for Disability	The CRPD is legally binding on those entities that ratify it. Key areas for action include health, participation and equality. The overall aim is to empower people with disabilities so that they can enjoy their rights and participate fully in society. The strategy identifies the support needed for funding, research, awareness-raising, statistics and data collection. The strategy will also ensure that persons with disabilities and their representative organisations are involved in the development and implementation of policies concerning them, given that the EU will also be implementing the CRPD (European Commission, 2010).
2009–2012	European Agency for Fundamental Rights (FRA) project on the fundamental rights of persons with intellectual disabilities and persons with mental health problems	The project is investigating how the fundamental rights of persons with mental health problems and persons with intellectual disabilities are safeguarded in the EU and where violations of rights occur. The FRA's research recognises the capacities of persons with mental health problems by incorporating them directly into its data collection process (European Agency for Fundamental Rights, 2009).
February 2009	European Parliament Resolution on Mental Health	The Resolution calls on Member States “to support and encourage the empowerment of organisations which represent people with mental health problems and their carers in order to facilitate their participation in the formulation and implementation of policy and in all stages of research into mental health” (European Parliament, 2009).
2009–2011.	WHO Europe and European Commission-funded project on service user and carer empowerment	One key component was supporting governments and local actors in creating an environment for user participation (World Health Organization Regional Office for Europe, 2011a).
2005	The Mental Health Declaration and Action Plan for Europe (WHO Ministerial Conference, Helsinki)	One priority was the recognition of the “experience and knowledge of service users and carers as an important basis for planning and developing services” (World Health Organization Regional Office for Europe, 2005).

“people receive effective and respectful treatment” that is “offered the way people want it”, the best way to assess what people want is to establish service users’ (and potential mental health service users’) meaningful engagement in the research used to address this question (e.g. MacInnes et al., 2011). If service users are to be involved in the development and evaluation of policy relating to them, as well as in research pertaining to them, there needs to be greater commitment to facilitating service users’ ability to participate in these activities. One powerful route to take is for countries to commit to building capacity in service user leadership in research and evaluation, such that service users can contribute to the commissioning, design, methodology, analysis and dissemination of mental health research, evaluation and monitoring. Research by service users has, in the last two decades, produced important new knowledge and developed innovative research methods. The challenge now is to build upon and extend more widely across Europe the existing service user research initiatives. The new mental health strategy for Europe should take up this challenge.

### **What has been achieved so far?**

In the last two decades, a number of research projects designed and undertaken by mental health service users have had a powerful impact on the mental health and social care field (e.g. Beresford et al., 2005; Faulkner & Layzell, 2000). The service user-led project directed by Rose (2001), for example, had an impact on local mental health services in England, and the collaborative systematic review, in which service user and clinical researchers investigated patients’ perspectives regarding electroconvulsive therapy (ECT) (Rose et al., 2003), influenced the subsequent development of National Institute for Health & Clinical Excellence guidelines on ECT in the UK. Projects such as these have developed new perspectives on what works and what does not work in improving service users’ lives, on what service users want from mental health services and on how to combat the discrimination and rights violations that they experience. Service user researchers have also developed robust guidelines to help ensure that research involving service user researchers is conducted in a just and ethical manner (Faulkner, 2004). They have emphasised the need to address the hierarchies in power between conventional researchers and service user researchers and have called for the empowerment of mental health service users to be an underlying goal in research projects involving service user researchers. They have argued that research approaches that conceptualise mental illness simply as individual pathology and dysfunction can perpetuate inequality and disempowerment and thus that the production of new knowledge and the transformation of some of the concepts used within psychiatry and mental health can be an influential route through which to achieve broader social transformations (Sweeney et al., 2009; Wallcraft et al., 2009).

Service user researchers have also anticipated many current policy priorities; for example, they have long argued that research needs to produce evidence and theory that can enable service users and carers to

- have a greater awareness of their situation so that they can make informed decisions and choices,
- have more control over the direction of their lives,
- participate more in social, economic and political life and
- challenge stigma, injustice and social exclusion

(Tew et al., 2006).

Mainstream mental health strategies and programmes now also commonly endorse these objectives as appropriate research outcomes.

A great amount has been achieved in terms of service user research in a relatively short space of time (Sweeney et al., 2009; Wallcraft et al., 2009). There are increasing opportunities for mental health service users across Europe to be involved in a variety of ways in research and in related fields such as evaluation and monitoring (Rose & Lucas, 2007) and the development of treatment guidelines (Harding et al., 2010), as well as growing acknowledgement by conventional mental health researchers of the importance of involving service users. However, service user involvement and leadership in research and evaluation activities are frequently hampered by inadequate funding and infrastructural and training support – and at times by outright hostility. Histories of various social movements demonstrate that those with power tend to be not willing to give it up. This argument has been made with respect to principal investigators in mental health research where service user researchers were involved and felt undermined (Beresford, 2003; Rose, 2003).

### **What is needed to promote service user leadership in research?**

Service user leadership in research currently exists only in a select number of European countries. Adequately recounting the history that lies behind areas of geographical concentration and areas of absence would take us beyond the scope of this editorial. We are personally aware of important service user-led research initiatives and/or service user leadership in research in Germany, the Netherlands, Norway, Slovenia and the UK: the fact, however, that we have been unable to find any published documentation that adequately maps such activities across Europe is itself arguably indicative of the need for additional support of service user leadership in research at a European level.<sup>1</sup> Evidence from countries (both within and beyond Europe) in which there already exists some hard-won service user leadership in research and in allied activities demonstrates a number of obdurate barriers that block growth and further dissemination of such leadership (O'Hagan, 2010). These include the negative attitudes of many clinicians and clinical academics; the explicit and subtle undermining of the legitimacy of service user positions and perspectives and ongoing difficulties with funding (Happell & Roper, 2006; Sweeney et al., 2009; Wallcraft et al., 2009).<sup>2</sup> For service user leadership in research to become more widespread, mental health researchers and policy-makers will need to take responsibility for providing structures and organisational frameworks that will serve to facilitate it. Countries are diverse, both in the extent of mental health research they conduct and in the strength and extent of service user groups and activity. Service user involvement and leadership in research will, therefore, necessarily vary by country. While the specific approaches taken need to be aware of these particularities, certain priorities are relevant for all European countries:

- (1) *Establish funding and other mechanisms to support service user leadership in research.* Possibilities to be considered include appropriate research training and development, mentoring, career pathways, capacity-building and funding streams. Organisations that support user involvement in research should be set up. A good example is INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) in England, which has institutional weight in that it is supported by the government. While INVOLVE is not mental health specific (it supports greater patient and public involvement (PPI) in all national health service, public health and social care research), a number of mental health service user researchers are prominent contributors to its work. The National Institute for Health Research (NIHR) in England also requires that grant applications demonstrate evidence of meaningful PPI and additionally uses “lay reviewers” in order to bring a patient perspective to all funding application reviews. In countries where funding is

scarce, other modes of support (e.g. in-kind) could be used to ensure the sustainability of research, evaluation and monitoring initiatives that have already been started. There is also much to be gained from the cross-fertilisation of approaches and initiatives between countries. Collaborative, international networks between service user researchers and between service user organisations and NGOs that are committed to service user empowerment (such as the Hungary-based, international human rights organisation Mental Disability Advocacy Center, which conducts participatory and emancipatory research) can assist in disseminating and extending good practice more widely. Service user-run, transnational organisations such as the European Network of (ex-)Users and Survivors of Psychiatry and the World Network of Users and Survivors of Psychiatry provide important forums for the cross-fertilisation of expertise and insights regarding service user research methods and perspectives.

- (2) *Utilise the specific expertise and insights of service users within the research arena.* Service user researchers must be regarded as credible producers of data and evidence, since mental health requires a greater variety of expertise than has traditionally been valorised in biomedical research. This will entail a reconsideration of what counts as scientific evidence and as mental health expertise. It must be recognised that mainstream research and clinical practice are not value free: the history, sociology and philosophy of medicine and science have amply demonstrated how different modes of research and clinical care establish different criteria (and hence values) through which to judge scientific rigour, the virtue of scientific and clinical practices and normative expectations regarding appropriate outcomes for medical interventions (e.g. Daston & Galison, 2007; Mol, 2002). It is, therefore, no criticism of service user research to say it is based on values (Sweeney et al., 2009).
- (3) *Transform hierarchies in mental health settings.* Hierarchies in mental health research and in clinical practice are often rigid. The long-standing power differentials between different categories of persons in clinical practice (with consultant psychiatrists typically with most power, psychologists and occupational therapists with less power, nursing/health care assistants with very little power and patients frequently entirely disempowered) are overlain in complicated ways by the axes of social class, gender and ethnicity. These power differentials are often carried over into and indeed sometimes given renewed energy within the research domain. They are further complicated by epistemological hierarchies (with principal investigators – who are frequently consultant psychiatrists – leading randomised controlled trials at one end of the hierarchy and qualitative, participatory researchers – some of whom are service user researchers – at the other end). Such structural inequalities can, therefore, make it difficult for the voices, expertise and knowledge of service users to be recognised (Happell & Roper, 2006). Partnership is espoused but often undermined – not least in scenarios in which some partners regard their own knowledge, expertise and authority as more valuable than those of other partners. One way to strengthen possibilities for service user involvement is through facilitating collaboration with existing disability and patients' rights movements, which are also pushing for service users to be regarded as full partners in health and social care interactions.
- (4) *Assess distribution of and control over resources.* It is important that service user researchers have opportunities to define research agendas, make decisions and control resources (rather than, as is much more common, work to agendas entirely determined by conventional researchers). Attention also needs to be paid to heterogeneity among service users (e.g. as regards gender, ethnicity, age and sexuality), so as to ensure that certain constituencies are not marginalised.

- (5) *Support service user organisations.* Much of the energy behind service user involvement in mental health research came from the social struggles surrounding deinstitutionalisation and, in particular, from service users' attempts to democratise mental health services and to redefine themselves as citizens and not simply as "psychiatric patients" (Sayce, 2000). (There is also a significant, though complicated, history of relationships between service user-led research in mental health and emancipatory research traditions established within the disability movement (Beresford & Wallcraft, 1997).) The connection between service user research and service user organisations has been strong from the start and remains so today. (For example, the majority of contributors to the edited collection *This is Survivor Research* (Sweeney et al., 2009) play active and significant roles in various service user organisations.) This history implies that one of the most powerful ways that mental health researchers, practitioners and policy-makers can nurture and enhance service user leadership in research is to support service user organisations and disabled people's organisations in their respective countries.

It is now commonplace to argue that strategies to improve mental health should plan actions that are based on research evidence. Acknowledgement that robust research evidence in this field includes research that draws directly on the experiences and insights of mental health service users is still infrequent. It is, however, essential. There have been, in the last few years, encouraging indications that European legislative and policy domains are moving in this direction. We call for the new strategy for mental health in Europe explicitly to endorse the necessity of service user leadership in mental health research.

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### **Notes**

1. We emphasise that there are undoubtedly other countries in which activities are taking place, of which we are unaware; our itemisation of countries should be taken as indicative rather than as authoritative.
2. Readers should be aware that we have not addressed the complex relationship between research *controlled* by service users/survivors and collaborative research *involving* service user researchers. While some of the barriers are shared by both kinds of research, there are also significant differences, which we are unable to discuss further here (Telford & Faulkner, 2004).



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