



EUROPE

WHO Regional Office for Europe

Empowerment in Mental Health – Working together towards Leadership

A meeting in partnership with the European Commission

Hosted by EUFAMI

27–28 October 2010, Leuven, Belgium

Mental health service user leadership in research

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Statement of topic and summary of issue

Service user leadership in research can make an important contribution to the empowerment of all mental health service users. Research by service users has produced new knowledge and contributed to the development of innovative methods of improving the lives and advancing the human rights of people with mental health problems. Service user research has also contributed to changing how mental ill health is conceptualized: it has challenged a model of mental illness as simply deficit and pathology and argued that "madness is a crisis of being that value and meaning can be derived from" (O'Hagan, 2009). Service users have argued that dominant research approaches to mental illness can perpetuate inequality and disempowerment. They have argued that the production of new knowledge and the transformation of the terms and concepts used within psychiatry and mental health can, therefore, be an influential route through which to achieve broader social and political change (Sweeney, Beresford et al., 2009; Wallcraft, Schrank et al., 2009). The challenge now for countries within the WHO European Region is to determine how best to ensure that existing service user research initiatives are built upon and extended more widely across the entire geographical region.

Background

In the last decade, a number of research projects designed and undertaken by service users have had a powerful impact on the mental health field (e.g. Faulkner and Layzell, 2000; Rose, Wykes et al., 2003; Shaping our Lives¹). These projects have developed new perspectives on what works and what does not work in improving the lives of service users and on what service users want from mental health services. Researchers have also developed robust principles and guidelines to help ensure that any mental health research involving service users is conducted in a just and ethical manner (Faulkner, 2004). They have emphasized the need to challenge hierarchies in power between traditional researchers and service user researchers and have explicitly called for the empowerment of mental health service users to be an underlying goal in any service-user-led research project (Beresford & Wallcraft, 1997).

In order for research to be emancipatory and contribute to the empowerment rather than the disempowerment of service users, it 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 (in conjunction with practitioners and members of the wider community) (Tew, Gould et al., 2006).

¹ Information available at: <http://www.shapingourlives.org.uk/about.html>.

Much of the energy behind service user involvement in mental health research came from the social and political struggles surrounding deinstitutionalization and, in particular, from service users' attempts to democratize mental health services and redefine themselves as citizens and not simply "psychiatric patients" (Sayce, 2000). The connection between service user research and the service user movement has been strong from the start and remains so today. This history implies that one of the most powerful ways that policy-makers and other stakeholders can nurture and enhance service user leadership in research is to support the service user movement in their respective regions and countries.

In terms of service user research, a great amount has been achieved in a relatively short space of time (Sweeney, Beresford et al., 2009; Wallcraft, Schrank et al., 2009). There are increasing opportunities for mental health service users across the WHO European Region to be involved in a variety of ways in research and related fields, such as evaluation and monitoring (Rose & Lucas, 2007) and there is growing acknowledgement within the mental health field of the importance of involving service users.

However, service user involvement and leadership in research are frequently hampered by inadequate funding and infrastructural support and, at times, by outright hostility. The histories of various social movements demonstrate that those with power tend not to be willing to give it up. This argument has been made with respect to principal investigators in mental health research where service user researchers were also involved and felt undermined (Beresford, 2003; Rose, 2003).

Concise analysis of the policy implications and policy options

Policy-makers can play a key role in assisting service user empowerment and leadership in research to become a reality throughout the WHO European Region rather than in – as is the case at present – only a select number of countries.

Countries within the WHO European Region are diverse both in terms of the extent of mental health research they conduct and in the strength and extent of service user groups and activities. Therefore, service user involvement and leadership in research will vary according to country. While it is necessary to be aware of these particularities in taking specific approaches, certain priorities are of relevance to all countries.

1. *In addition to training service users and empowering them to adopt standard research roles, bring their specific expertise and insights to the centre of the research arena.* This will entail a larger shift regarding what counts as scientific evidence and who the experts within mental health are. Service users must be regarded as credible producers of evidence and an authority, since mental health requires a much greater variety of expertise than has been valorized in traditional, biomedical research. It must be recognized that mainstream research is not value-free and, therefore, it is no

criticism of user research to say that it is based on values (Sweeney, Beresford et al., 2009).

2. *Transform existing professional structures and traditional hierarchies in mental health settings.* The often rigid hierarchies in the research establishment can make it almost impossible for the voices of service users to be heard and for their expertise and knowledge to be recognized (Happell & Roper, 2006). Partnership is espoused but often undermined. One powerful way in which to build the foundations of service user involvement is through collaboration with existing patients' rights movements and other movements that aim to address the power imbalances in mental health and ensure that service users are regarded as full partners in all interactions (Tait and Lester, 2005; Lewis, 2009).

These two goals will take time to achieve and development will vary between countries in the Region. In the meantime, there are different ways of involving service users in mental health research, for example, in relation to governance, commissioning, funding, management, research, training, evaluation (Annex 1). There is a distinction between service-user-led research and collaborative research, which is often determined by the location of the research: in universities, research is largely collaborative, whereas in nongovernmental organizations (NGOs) it can be service-user-led. Policy-makers can nourish research and leadership where research is user-led as well as collaborative.

Conclusions and recommendations for action

Policy-makers can facilitate links with "allies", such as general patients' rights movements and those working towards deinstitutionalization. It is not by accident that the best established records in user empowerment and leadership in research are to be found in countries where deinstitutionalization took place early.

Policy-makers should establish funding and other mechanisms to support service user involvement and leadership in research. Possibilities to consider include appropriate training and development, mentoring, development of career pathways and capacity-building. Organizations that support user involvement in research should be set up. A good example is INVOLVE² in England, which has institutional weight in that it is supported by government. In countries where funding is scarce, other modes of support should be set up to ensure the sustainability of initiatives already started. There is also much to be gained from the cross-fertilization of approaches and initiatives between countries within the WHO European Region. Collaborative, international networks between service user researchers and between service user organizations and NGOs committed to service user empowerment and the advancement of service users' human rights can assist in disseminating and extending good practice more widely.

² Information available at: www.invo.org.uk.

It is necessary to work to transform the distribution of power and resources, including the equal distribution of collective power and the empowerment of individuals and groups. Policy-makers should ensure that people with mental health problems have the power to set the agenda, make decisions and control resources. This will often mean supporting user-led initiatives. It is also essential to attend to the heterogeneity among service users (gender, ethnicity, age, sexuality).

There are, in addition, legislative and policy tools that can support the empowerment of service users, including the United Nations Convention for the Rights of People with Disabilities. The European Pact for Mental Health and Well-being notes that "people who have experienced mental health problems have valuable expertise and need to play an active role in planning and implementing actions", and calls on policy-makers and stakeholders to "involve people with mental health problems and their families and carers in relevant policy and decision-making processes". The emphasis should be placed on planning actions based on research evidence. This is not controversial. Ascribing a central place in this process to service users is more novel.

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Annex 1. Examples of service user involvement in mental health research

Researcher/team	Description of activities	User involvement	Strengths	Drawbacks
Institutional Treatment and General Care (ITHACA) in 16 European countries	Developing a tool to monitor human rights in institutions for people with mental health and intellectual disabilities	(1) Focus groups conducted and analysed by service users fed into the monitoring tool (2) Site visits (6 in each of the 16 countries) always include a service user monitor (3) One PI a service user	User involvement at each step of developing and piloting the tool Importance of service user involvement in research disseminated widely, also in countries with no previous history of service user involvement	Multidisciplinary Project Management Team (psychiatrists, lawyers and a service user researcher) did not always work well
Service User Research Enterprise (SURE) Institute of Psychiatry King's College London	Collaborative research endeavour between service user and non service user researchers – balanced management structure	(1) Patient-centred systematic reviews (2) User-generated outcome measures (3) Exit interviews with participants in biomedical trials/ informed consent)	Majority of employees have been users of mental health services as well as being researchers. "Insider knowledge" gives a new perspective not only empirically but also epistemologically	None of the service user researchers is as senior as the clinician co-director
Centre for Excellence in Interdisciplinary Mental Health (CEIMH) Birmingham England	Carries out work at national, international and local levels to promote the importance of the service user voice in research and teaching	(1) Conferences for delegates from overseas to include user researcher delegates (2) High-profile seminars (these have included user speakers from overseas (not Europe)	A large contingent of users works with CEIMH stemming from a long-standing user-led research and teaching group called SURESearch	(1) Welfare benefit regulations in England inhibit proper payment for service users 2) Most full-time employees are not service users
PARITÄTISCHEN Berlin Germany	Strong user-led research	Collaborative work with persons who have experienced homelessness and psychiatry at all stages of research	Independent of university hierarchies (the above three projects are all based in universities)	1) Fragile funding 2) Outcomes not taken seriously