

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

This is a pre-copy-editing, author-produced PDF of an article accepted for publication in *The Journal of Mental Health* following peer review. The definitive publisher-authenticated version (Callard F & Rose D (2012) 'The mental health strategy for Europe: why service user leadership in research is indispensable' *Journal of Mental Health* 21(3): 219–226 (doi:10.3109/09638237.2011.651661) is available online at: <http://informahealthcare.com/doi/abs/10.3109/09638237.2011.651661>

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.

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 one of the proposed four core strategic objectives of the strategy 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 (See Table 1) that emphasize the indispensability of service

user involvement in the development, implementation and evaluation of policies that relate to service users. The European Parliament Resolution on Mental Health in 2009 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’.

*** * * * * INSERT TABLE 1 NEAR HERE * * * * ***

Table 1: European Declarations, Strategies and Projects that emphasize service user involvement

Date of adoption /ratification; or time period of strategy or project	Declaration, Convention, strategy or project	Specifications re service user involvement
December 2010	Ratification by the European Union of the UN Convention on the Rights of Persons with Disabilities (CRPD)	<p>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.</p> <p>The CRPD is legally binding on those entities that ratify it.</p>
2010–2020	European Union Strategy for Disability	<p>Key areas for action include health, participation and equality.</p> <p>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.</p> <p>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).</p>
2009–2012	European Agency for Fundamental Rights (FRA) project on the fundamental rights of persons with intellectual disabilities and persons with mental health problems	<p>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.</p> <p>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).</p>
February 2009	European Parliament Resolution on Mental Health	<p>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).</p>
2009–2011	WHO Europe and European Commission funded project on service user and carer empowerment	<p>One key component was supporting governments and local actors in creating an environment for user participation (World Health Organization Regional Office for Europe, 2011a).</p>
2005	The Mental Health Declaration and Action Plan for Europe (WHO Ministerial Conference, Helsinki)	<p>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).</p>

These declarations, strategies and projects emphasize 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 ‘people receive effective and respectful treatment’ that is ‘offered the way people want it’, the best way in which 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, Beer, Keeble, Rees, & Reid, 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 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, Shamash, Forrest, Turner, & Branfield, 2005; Alison 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, Wykes, Leese, Bindman, & Fleischmann, 2003), influenced the subsequent development of National Institute for Clinical and Health Excellence (NICE) guidelines on ECT in the United Kingdom. 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 emphasized 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 conceptualize 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, Beresford, Faulkner, Nettle, & Rose, 2009; Wallcraft, Schrank, & Amering, 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
- 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 (see 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, Brown, Hayward & Pettinari, 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, infrastructural and training support – and at times by outright hostility. Histories of various social movements demonstrate that those with power tend not willingly 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 in only a select number of European countries. Adequately to recount 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 United Kingdom: 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.¹ 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 (see 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).² For service user leadership in research to become more widespread, mental health researchers and policy makers

¹ We emphasize that there are undoubtedly other countries in which activities are taking place, of which we are unaware; our itemization of countries should be taken as indicative rather than 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 (see Telford & Faulkner, 2004).

will need to take responsibility for providing structures and organizational 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 consider 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) in England, which has institutional weight in that it is supported by government. While INVOLVE is not mental health specific (it supports greater patient and public involvement 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 patient and public involvement (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-fertilization 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 organization Mental Disability Advocacy Center, which conducts participatory and emancipatory research), can assist in disseminating and extending good practice more widely. Service-user-run, transnational organizations such as the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP) and the World Network of Users and Survivors of Psychiatry (WNUSP) provide important forums for the cross-fertilization of expertise and insights regarding service user research methods and perspectives.

2. *Utilize the specific expertise and insights of service users within the research arena.* Service users 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 (RCTs) 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 recognized (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 amongst service users (e.g. as regards gender, ethnicity, age, sexuality), so as to ensure that certain constituencies are not marginalized.

5. *Support service user organisations.* Much of the energy behind service user involvement in mental health research came from the social struggles surrounding deinstitutionalization, and in particular from service users' attempts to democratize mental health services and to redefine themselves as citizens and not simply '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 (see 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 organizations and disabled people's organisations (DPOs) 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.

References

- Beresford, P. (2003). *It's Our Lives: A short theory of knowledge, distance and experience*. London: Citizen Press, in association with Shaping Our Lives.
- Beresford, P., Shamash, M., Forrest, V., Turner, M., & Branfield, F. (2005). *Developing social care: service users' vision for adult support*. Bristol: Social Care Institute for Excellence / Policy Press.
- Beresford, P., & Mercer, G. (1997) Psychiatric system survivors and emancipatory research: issues, overlaps and differences. In: Barnes, C., & Mercer, G. (eds) *Doing Disability Research*. Leeds: The Disability Press, pp. 66–87.
- Daston, L., & Galison, P. (2007). *Objectivity*. New York: Zone.
- European Agency for Fundamental Rights. (2009, 8 April 2011). Fundamental rights of persons with intellectual disabilities and persons with mental health problems. Retrieved 12 April, 2011, from http://www.fra.europa.eu/fraWebsite/research/projects/proj_disability_en.htm
- European Commission. (2010). *European Disability Strategy 2010–2020: A renewed commitment to a barrier-free Europe*. COM(2010) 636 final. Brussels: European Commission.
- European Parliament. (2009). *Resolution on Mental Health*. P6_TA-Prov (2009) 0063. A6-0034/2009: European Parliament.
- Faulkner, A. (2004). *The ethics of survivor research: guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Bristol/York: The Policy Press/Joseph Rowntree Foundation.
- Faulkner, A., & Layzell, S. (2000). *Strategies for Living: A report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.
- Faulkner, A., & Thomas, P. (2002). User-led research and evidence-based medicine. *British Journal of Psychiatry*, 180, 1–3.
- Happell, B., & Roper, C. (2006). The myth of representation: the case for consumer leadership. *Australian e-Journal for the Advancement of Mental Health*, 5(3), 1–8.
- Harding, E., Brown, D., Hayward, M. & Pettinari, C.J. (2010) Service user perceptions of involvement in developing NICE mental health guidelines: a grounded theory study. *Journal of Mental Health*, 19(3), 249–257.
- MacInnes, D., Beer, D., Keeble, P., Rees, D., & Reid, L. (2011). Service-user involvement in forensic mental health care research: areas to consider when developing a collaborative study. *Journal of Mental Health*, 20(5): 464–72.
- Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham and London: Duke University Press.
- Muijen, M. (2011). Announcement European Mental Health Strategy, Berlin 4th of March 2011. Retrieved 12 April, 2011, from http://ec.europa.eu/health/mental_health/docs/ev_20110303_co48_en.pdf

- O'Hagan, M. (2010) Leadership for empowerment and equality: a proposed model for mental health user/survivor leadership. *International Journal of Leadership in Public Services*, 5(4), 34–43.
- Rose, D. (2001). Users' Voices: The perspectives of mental health service users on community and hospital care. London: The Sainsbury Centre for Mental Health.
- Rose, D. (2003). Collaborative research between users and professionals: peaks and pitfalls. *Psychiatric Bulletin*, 27(11), 404–406.
- Rose, D., & Lucas, J. (2007). The user and survivor movement in Europe. In M. Knapp, D. McDaid, E. Mossialos & G. Thornicroft (Eds.), *Mental Health Policy and Practice across Europe: The future direction of mental health care* (pp. 336–355). Maidenhead, Berkshire: Open University Press.
- Rose, D., Wykes, T., Leese, M., Bindman, J., & Fleischmann, P. (2003). Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ*, 326, 1363-1366.
- Sayce, L. (2000). *From psychiatric patient to citizen: overcoming discrimination and social exclusion*. Basingstoke and New York: Palgrave.
- Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., & Rose, D. (Eds.). (2009). *This is Survivor Research*. Ross-on-Wye: PCCS Books.
- Telford, R., & Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health* 13(6), 549–559.
- Tew, J., Gould, N., Abankwa, D., Barnes, H., Beresford, P., Carr, S., et al. (2006). *Values and methodologies for social research in mental health: Social Perspectives Network*.
- Wallcraft, J., Schrank, B., & Amering, M. (Eds.). (2009). *Handbook of Service User Involvement in Mental Health Research*. Chichester: Wiley-Blackwell.
- World Health Organization Regional Office for Europe. (2011a). Mental health: Empowerment of service users and carers. Retrieved 12 April, 2011, from <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/activities/empowerment-of-service-users-and-carers>
- World Health Organization Regional Office for Europe (2011b) Policy: European mental health strategy. Retrieved 8 December, 2011, from <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/policy/european-mental-health-strategy>
- World Health Organization Regional Office for Europe. (2005). *Mental Health: Facing the challenges, building solutions. Report from the WHO European Ministerial Conference, 2005*. Copenhagen: World Health Organization Regional Office for Europe.

Declaration of interest Both FC and DR were invited to present at a WHO/EC-funded conference on service user leadership and empowerment in 2010, and their travel expenses were covered by WHO Europe. Subsequent to the writing of the editorial (and while it was undergoing peer review), FC was invited by WHO Europe

to draft some of the sections of the forthcoming Mental Health Strategy. FC is Chair of the Board of Trustees of the Mental Disability Advocacy Center.

Acknowledgements and sources of funding

The authors acknowledge financial support from the National Institute for Health Research (NIHR) Specialist Biomedical Research Centre for Mental Health award to the South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, King's College London. This funding source had involvement neither in the writing of this editorial nor in the decision to submit it for publication.