

<p>Institution: Anglia Ruskin University</p>
<p>Unit of Assessment: 22 Social Work and Social policy</p>
<p>Title of case study: Involving peer led self-help groups and citizen research groups in the improvement and development of services</p>
<p>1. Summary of the impact</p> <p>Our research has had a direct influence on policy makers', commissioners' and practitioners' understanding of the value of peer led self-help groups and the potential of citizen/service user researchers for driving service improvements grounded in lived experience. That impact is reflected in:</p> <ul style="list-style-type: none"> ➤ national and local guidelines ➤ national and local training initiatives ➤ the sustained commissioning of two service user/citizen research groups and related service improvements ➤ increased social capital and skills for the citizens involved.
<p>2. Underpinning research</p> <p>We have developed participatory methodologies that ensure that the unique experiential knowledge service users and carers have as individuals and in groups can best inform health and social care practice and service development. Our work contributes to this field through two main areas:</p> <p>Involving peer led self-help groups and organisations in developing an evidence base of their distinctive contribution to the welfare landscape (<i>Munn-Giddings and Boyce</i>)</p> <p>Building on a cross-national study (UK, US, Sweden 2006-2008) reported in RAE 2008, we have developed our research into the type of knowledge and practices that characterise peer led self-help groups and organisations by focusing upon their innovative and unique features (<i>Boyce et al. 2010</i>). Our specific contribution to the field is in reconceptualising self-help as a form of voluntary action rather than (as was commonly the case in the UK) an adjunct to professional services. We have also identified the unique forms of reciprocal support and social relations that can be provided by peers that cannot be replicated in professional services (<i>Borkman, Munn-Giddings et al. 2009</i>). In addition we are continuing to identify the contribution that self-help/mutual aid activities can make to the social support and wellbeing of 'active members', demonstrating that the reciprocity/mutuality ethos enacted in groups can enhance mental wellbeing and recovery not through individual agency but in a balance between individual and collective responsibility exercised through community networks (<i>Seebohm et al. 2012</i>). Through on-going cross-national collaborations we have been exploring how national policies and funding environments have impacted on the ability of self-help organisations to retain their self-help/mutual aid ethos and working practices.</p> <p>Two projects have specifically contributed to this work, <i>The Innovatory Features of User Run Organisations</i>, funded by the Mental Health Foundation (2008-10) and the <i>Effective Support for Self Help / Mutual aid groups</i> (ESTEEM) Big Lottery funded project, the latter undertaken in collaboration with Self Help Nottingham (SHN) and The University of Nottingham (2010-13). In addition we have explored and threaded the theme of peer support through other funded work that focuses on service user involvement in commissioning <i>Making Involvement Matter in Essex</i> (MIME) (2009-12). All of these projects have been designed to include service users and carers in the definition of issues being studied, either through active membership of steering groups and advisory boards and/or as participants in the collection, analysis and interpretation of data.</p> <p>Developing peer led Citizen Research Groups (<i>Munn-Giddings, Secker, Boyce, O'Brien, Moules, Ramon & Anghel</i>)</p> <p>A further related innovation and strength of our service user involvement has been our participatory approaches to training and supporting citizen research groups across the life course (<i>O'Brien and Moules 2007; Boyce et al. 2009</i>). We involve young people, older people and people experiencing mental distress in all stages of the research process to ensure their experiential knowledge informs</p>

the research questions we pose, the way in which we undertake research and the implications we draw from research findings. Our work adds to methodological understandings as to how best to involve citizens in research to ensure their experiential knowledge enhances the research process and quality of data. We have not only demonstrated that marginalised groups can undertake their own research given the right support and training, but also explored the methodological challenges and benefits inherent in this work. This work has been funded and developed in close partnership with local health trusts and Essex County Council (ECC) to ensure sustainability of the initiatives (e.g. Skills for Care/Essex County Council, 2007-2011 and South Essex Partnership University NHS Foundation Trust, on-going from 2005) (SESURG, Secker and Gelling 2006).

Key researchers:

Carol Munn-Giddings, Professor of Participatory Research & Collaborative Practices (2009-present); Shula Ramon, Emerita Professor of Social Work (Emeritus status from 2009); Jenny Secker, Professor of Mental Health (2002 to present); Melanie Boyce, Research Fellow (2004 to present); Niamh O'Brien, Research Fellow (2004 to present); Tina Moules (previously Director of Research 2001 to 2012); Roxana Anghel (2004 to present).

3. References to the research (indicative maximum of six references)

O'Brien, N. and Moules, T. (2007) So round the spiral again: a reflective participatory research project with children and young people, *Educational Action Research Journal* 15 (3), pp. 385-402. DOI: 10.1080/09650790701514382

Borkman, T., **Munn-Giddings, C.**, Karlsson, M., Smith, L. (2009) Social Philosophy and Funding in Self Help Organisations: A US-UK-Swedish analysis. *International Journal of Self Help and Social Care*, 4 (3), pp 201-220. DOI: 10.2190/SH.4.3.c

Seebohm, P., **Boyce, M.**, Chaudhary, S., Avis, M. and **Munn-Giddings, C.** (2012) The contribution of self-help/mutual aid groups to mental wellbeing. *Health & Social Care in the Community*. DOI: 10.1111/hsc.12021.

Boyce, M., Munn-Giddings, C., Campbell, S. and Smith, L., 2010. Innovatory features and challenges facing mental health user-led organisations. *Mental Health Review Journal*, 15 (2), pp. 34-42. DOI: 10.5042/mhrj.2010.0370

Boyce, M., O'Brien, N., Munn-Giddings, C. and McVicar, A., 2009. How does the rhetoric of 'user participation' in research apply to older people? *Research, Policy and Planning*, 27 (2), pp 55-63.

Can be supplied by the HEI on request.

SE-SURG, Secker J. and Gelling L. (2006) Still dreaming: service users' employment, education & training goals. *Journal of Mental Health* 15: 1: 103-111. doi:10.1080/09638230500512508

Quality of the research

The outputs listed are all published in peer reviewed academic journals and all authors consistently published in highly rated journals. Before funding proposals are submitted Anglia Ruskin University requires a rigorous peer review by academic colleagues with an appropriate subject or methodological specialism. National research funding (Big Lottery and Mental Health Foundation) was successfully obtained via a blind peer review process. Regional funding calls are reviewed by subject experts in the field and in addition the MIME project required an assessed presentation to an interdisciplinary panel of commissioners, practitioners and service users. The Big Lottery ESTEEM project was selected in 2011, through a competitive process, by the Research Councils UK and Universities UK as a project that exemplifies research demonstrating the value of public investment in higher education and research and the positive impact this has on economic growth and the social wellbeing of the UK.

4. Details of the impact

Peer led Self-Help Groups and Organisations

Our research with and into peer led self-help groups and organisations has directly influenced

national and regional initiatives aimed at improving health and social care commissioners' understanding of the value, role and spectrum of self-help groups. Findings from our research on the benefits of peer led groups and organisations have been included in the Social Care Institute for Excellence (SCIE) national guidelines for commissioners on developing and sustaining user-led organisations. In addition, findings from the Big Lottery-funded ESTEEM project have been dovetailed with a Department of Health project to develop a national online tool kit for practitioners on the most effective ways to develop and support local self-help groups. Following completion of the research, online and paper resources for self-help groups, practitioners and commissioners, hosted by Self Help Nottingham (SHN), were launched at Anglia Ruskin University in July 2013 and have formed the basis for training targeted at health and social care workers, criminal justice personnel, third sector agencies and key members of patient groups. Eighty-four people to date have completed the training (corroborative statement from SHN). Four regional seminars on the core findings from the research have ensured that links have been made for audiences of commissioners and community practitioners between support for self-help groups and current policy initiatives such as personalised care and support for people with long term conditions. SHN have presented the findings at the European Network for Self Help and are planning a national event for 2014. The ESTEEM research has also informed an accredited course, delivered by our partners SHN, the national specialists in the field, at the Nottingham University's Institute of Mental Health in May 2013, for professionals in mental health on working with self-help groups. This study is also informing Nottingham's Local Education Training Board in supporting the NHS to integrate training on ways in which professionals can support self-help groups. The practical application and impact of the ESTEEM study was recognised with inclusion in the *Big Ideas for the Future 2011* report, jointly published by the Research Councils UK and Universities UK. At the local level, Essex-based health and social care commissioners have written initiatives that support peer led groups into their service specifications (MIME 2012; corroborative statement from Head of Mental Health Commissioning, ECC).

Peer/Citizen Researchers

Prominent examples of the impact of involving service users as researchers have been the sustained commissioning of two peer/citizen research groups (CRGs) and the formation in 2011 of a third group. These groups are:

1. The South Essex Service User Research Group (SE-SURG), a group of mental health service users, was established at Anglia Ruskin University in 2005 following their involvement with the employment survey detailed in our second case study. SE-SURG have carried out 14 further studies commissioned to inform local service development during 2008 -2013, with support from Secker.
2. WhyNot!, an older people's Research Group, was established in 2007 and built on our initial training programme for older people as researchers. Twenty-two people completed the training, of whom 10 were founding members in the self-organising Research Group. Since 2008 they have carried out 14 projects as direct commissions from the County Council, District Councils, NHS and Age UK which we have supported on a 'needs-led' basis. Two further cohorts have been trained between 2009 and 2011 (Munn-Giddings, McVicar, O'Brien & Boyce).
3. The North Essex Research Network, a group of mental health service users similar to SE-SURG, was established in 2012, following training in research provided as part of the Making Involvement Matter in Essex (MIME) project (2009-2012). The group has nine members and completed several studies under the auspices of MIME, with a further two evaluations of recovery initiatives commissioned in 2013 by the NHS Greater Eastern Commissioning Support Unit (Secker and Munn-Giddings).

Feedback from commissioners demonstrates their increased awareness of the positive advantages of peer research and their policy commitment to developing peer researchers in other parts of their adult services. For example, with our support Healthwatch Essex is developing the model with broader citizen groups to inform strategic planning (corroborative statement from Head of Research and Analysis, ECC). In addition both WhyNot! and SE-SURG research projects have

informed changes in practice at a local level. For example, WhyNot! was commissioned to research into technologies that help older people remain in their home. The study resulted in the Council targeting practitioner training as well as developing a demonstration facility, both of which have led to an uptake in the service. Similarly, several studies carried out by SE-SURG have had a local impact, for example in supporting the modernisation of day services in South Essex, resulting in a shift away from staff-led building-based services towards peer support and use of mainstream community facilities. Subsequent evaluation found high levels of satisfaction with the new services amongst day service users.

Feedback from members of these Citizen Research Groups highlights personal impacts including improved confidence, new skills, employment opportunities and feeling empowered to influence change (WhyNot! corroborative statement; SE-SURG Activity Report 2008-2013). Further impact has stemmed from replication of SE-SURG's employment survey and the associated pioneering engagement of service users as researchers within the Department of Psychiatry at the University of Pavia (see our second case study). The value of service user involvement in research has been recognised in subsequent studies carried out at the University of Pavia.

Recognition of the quality of SE-SURG's and WhyNot!'s work by Essex Health and Social Care Commissioners is evidenced by an invitation to Secker and Munn-Giddings in 2009 to tender successfully for a £500,000 three-year initiative aimed at extending service user involvement in commissioning decisions. This initiative, Making Involvement Matter in Essex (MIME), was delivered in partnership with a user-led training organisation ARW (Advocacy Really Works) and enabled us to engage a wider group of service users and carers in research. Twenty MIME members received training in research skills in 2011, of whom, as noted above, nine formed the North Essex Research Network and have carried out studies with impact on commissioning strategy and service development in Essex, for example introduction of a helpline web chat service for younger people. As with SE-SURG members, personal benefits identified in feedback from MIME members include improved confidence and feeling useful and empowered to influence change (MIME, 2012).

As well as supporting the development of research skills these types of initiatives develop social capital and skills amongst service users and carers which they put to use in many ways. For example, members of WhyNot! now sit on Essex County Council's Research and Governance Committee and have used their training in their local communities to carry out a local community consultation that increased rural transport options (WhyNot! corroborative statement). This highlights the potential of this approach to build skills that can inform and impact on other democratic processes.

4. Sources to corroborate the impact

1. ESTEEM Web based tool kit (available on the SHN website www.selfhelp.org.uk/esteem)
2. SE-SURG activity report (2008-13) <http://hdl.handle.net/10540/301637>
3. Big Ideas for the Future RCUK (2011) www.rcuk.ac.uk/documents/publications/BigIdeasfortheFuturereport.pdf
4. MIME (2012) *Evaluation of the MIME Project*. <http://hdl.handle.net/10540/304944>
5. **Munn-Giddings, C** & McVicar, A., Boyce, M., O'Brien. N., 2009. Older People as Researchers – WhyNot?. *Working with Older People*, 13 (4), pp 16-19. (Available from the HEI on request)
6. www.scie.org.uk/publications/guides/guide36/resources/

Plus corroborative statements from individual users/beneficiaries (all available from the HEI on request):

1. WhyNot! Older People's Research Group
2. Head of Research and Analysis, Essex County Council
3. Head of Mental Health Commissioning, Essex County Council
4. Director of Self Help Nottingham