

<b>Institution:</b> Queen's University Belfast
<b>Unit of Assessment:</b> 22 - Social Work and Social Policy
<b>Title of case study:</b> Hearing the voice of the User: Influencing policy through participation
<p><b>1. Summary of the impact</b></p> <p>The importance of public and user involvement in the development and delivery of research, policy and practice is now widely recognised. Nonetheless, service providers continue to experience difficulties in meaningfully involving service users and carers in their work in spite of the fact that this is a legal and policy requirement. Researchers, policy makers and providers do not always have the knowledge and skills effectively to involve the public and service users and carers. This case study describes the very significant impact of one piece of research designed to address these challenges in Northern Ireland. This research is presented as an example of impact because it has resulted in significant changes to the policies and practices of the three key organisations funding the research.</p>
<p><b>2. Underpinning research</b></p> <p>User and public involvement has been a longstanding focus of staff at Queen's with a number of examples available of innovative work in this area. One piece of research, commissioned by the Social Care Institute for Excellence, London, on behalf of the Regulation and Quality Improvement Authority (RQIA), and the Northern Ireland Social Care Council (NISCC) was awarded to Mr Joe Duffy (Lecturer in Social Work) after a competitive peer review process.</p> <p>The research team led by Duffy (Principal Investigator) consisted of academic and service user/peer researchers. The key purpose of this research was to recommend ways in which user involvement in Northern Ireland could be strengthened. The organisations providing the £14k funding for the research were keen to be presented with a range of options for the further inclusion and participation of users in their work. They were also requesting a focus on the strategic development of user involvement in Northern Ireland more broadly (<a href="#">See Reference 1</a>)</p> <p>A significant aspect of this research was that it was undertaken jointly by a team consisting of academic and service user/peer researchers. All key aspects of the research process were therefore jointly organised by academics and service user researchers applying different elements of their expertise. In this way there was a true spirit of collaboration to the research approach where team members could learn from each other's experience. Service user researchers were therefore fully involved in the interviews, data analysis, report writing and development of conclusions and recommendations (<a href="#">See Reference 3</a>)</p> <p>The research used a multi-method approach to data collection, combining desk-based research and interviews with 148 people from a range of service user and carer groups across Northern Ireland. Our review of the literature indicated that more attempts needed to be made by researchers and policy makers to include the views of groups and individuals experiencing social exclusion and marginalisation. Our research therefore took particular care to ensure that 'seldom heard' user groups were consulted. The research made a total of eight key recommendations (<a href="#">See Reference 1</a>). Several of these related to issues such as improvements in staff training and awareness, the need for key staff being identified for implementing user issues and the need for senior management to take strategic responsibility for directing and implementing policies and practices on user involvement.</p> <p>One recommendation, in particular, relates significantly to the impact in this case study. The research highlighted that the three organisations commissioning the research needed to clearly and actively communicate their roles and responsibilities to service users and carers involved in their work and also in the wider community.</p>

**Impact case study (REF3b)**

The majority of respondents surveyed in this research had indicated that they had encountered serious difficulties in how the health and social services organisations communicated with them. This recommendation was in direct response to this issue.

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

(Reference 1) Duffy, J. (2008) *Looking Out from The Middle: User Involvement in Health and Social Care in Northern Ireland*. London: Social Care Institute for Excellence (SCIE). Available at: <http://www.scie.org.uk/publications/reports/report18.asp>. This research was funded by the award of £14,000 to Queen's University from SCIE after a competitive process which involved rigorous peer review.

(Reference 2) (SCIE, 2008) *Strengthening user involvement in Northern Ireland: a summary and action plan*. London: Social Care Institute for Excellence. Available at: <http://www.scie.org.uk/publications/reports/report18.asp>

(Reference 3) Duffy, J. and Mc Keever, B. (2012) 'Looking out from the middle: Influencing policy change through user involvement.' In Barnes and Cotterell (eds.) *Critical Perspectives on User Involvement*. pp.101-114. Bristol. The Policy Press.

**4. Details of the impact**

The publication of an Action Plan (SCIE, 2008) (See Reference 2 above) based on the research findings showed that those funding the research were serious about implementing the research recommendations. The following quote from SCIE underscores the legacy of this research in terms of its impact: "*SCIE was delighted to be involved in the partnership work which led firstly to the publication of Looking out from the Middle and then to the establishment of annual conferences which aim to strengthen user and carer involvement in health and social care in NI. The publication of this research was a key moment in the systematic and strategic development of user and carer involvement in NI. It was symbolic and practical; symbolic in that RQIA, NISCC and SCIE jointly made a public commitment to user involvement and practical in that this was combined with a focused and specific Action Plan. The annual conferences embody this commitment and are an opportunity for users and carers to hold RQIA, NISCC and SCIE to account, reflect on progress and share learning*" (From Reference 3): Duffy and Mc Keever (2012:112)

All three organisations have now changed their policies and working practices on user engagement and public participation as a result of this research. Specific examples are as follows:

**Example 1.** Since the research was published in 2008, an annual User Involvement Conference funded and organised by the three commissioning organisations now takes place. This conference is jointly organised with service user representatives and is a direct response to the research recommendation that health and social care service providers need to more actively engage and communicate with the public in Northern Ireland. The most recent conference was opened and endorsed by the Northern Ireland Health Minister (Mr Edwin Poots). As a reflection of this event's impact and importance, the Patient and Client Council in Northern Ireland, the watchdog organisation for service users' issues, have now committed to leading on the organisation of the 2013 conference. The conference routinely involves presentations by service users about their experiences of receiving services and always includes opportunities for a 'question time' panel debate with senior managers from the health and social care sector through which service users can directly interface with and challenge service providers.

**Example 2.** User involvement practices are now firmly embedded in the working practices of RQIA. *Patient Experience Reviews* now routinely take place before inspections; service user views on the experiences of Guardianship are also sought and care experienced young people with a learning disability are involved in inspections of residential care facilities. The following quote from RQIA further highlights the impact of this research: *“This research has been a catalyst for us to ensure that we put service users and carers at the heart of what we do in all our regulation, inspection and review activities and by ensuring the voice of the user is reflected we can qualitatively reflect their experience to those who care for them or provide them with a service. We have seen tremendous evidence of real and meaningful and enhanced service improvements particularly on long stay mental health and learning disability wards”.*

**Example 3.** The establishment of a Participation Group in the Northern Ireland Social Care Council (NISCC) whose work is directly impacted by the research findings. *“The NISCC Participation Group is taking forward and further developing the Council’s user and carer agenda and addressing the recommendations of the ‘Looking out from the Middle’ research into effective user involvement which was undertaken by the Queen’s University Belfast in 2008”.* (www.niscc.info)

Involvement as co-researchers has also had positive outcomes for several of the service users involved as the following quotes evidence:

*“The research had a number of tangible outcomes for us, the experience of working as peer researchers, being able to influence three large organisations who actually took on board what was being said and acted on it and the legacy of the research for us was the confidence it gave people to take on a more strategic role in the three organisations”* (Service User Researcher)

*“At a personal level, coming from a User background, the impact of having been involved in this research has had a long term impact on me. As someone who was directly involved, as a user researcher, I got a tangible sense that I was valued as a person and that my experience of life was acknowledged as being important. For me, this research has become a model of good practice and a template that others could learn from.”* (Service User Researcher)

Service user researchers have also co-presented with Duffy at international and national conferences disseminating the research findings.

1. *Critical Perspectives on User Involvement, Health and Social Policy Research Centre, University of Brighton, April 2009. Presentation by Duffy with Brendan Mc Keever (service user researcher). Following this, Duffy and Mckeever were invited to contribute to the Policy Press text Critical Perspectives on User Involvement, Edited by Marian Barnes and Phil Cotterell.*
2. *ASA10 (Association of Social Anthropologists of the UK and Commonwealth): The Interview - theory, practice, society, Queen's University, Belfast, 13/04/2010 – 16/04/2010. Panel Presentation – The use of the Interview by service user researchers with marginalised groups by Duffy, J. Cushley, P. (service user researcher) and McGlone, A. (service user researcher)*

*Getting It Right – Effective Carer Involvement. Carer’s Northern Ireland. 29th November, 2011, Grosvenor House, Belfast. Key note address by Joe Duffy and Brendan Mc Keever (User Researcher).*

**5. Sources to corroborate the impact****Personal Sources**

- Chief Executive, Northern Ireland Social Care Council
- Participation Manager, Social Care Institute for Excellence
- Director of Quality Assurance and Chief Advisor for Social Work, Regulation and Quality Improvement Authority, Belfast.
- Manager, Willowbank Community Resource Centre.
- User Researcher

**Documentary Sources**

Duffy, J and Mc Keever, B (2012) Looking out from the middle: Influencing policy change through user involvement. In Eds Marian Barnes and Phil Cotterell. Critical Perspectives on User Involvement. pp.101-114. Bristol. The Policy Press.

[http://www.niscc.info/content/uploads/downloads/news/NISCC\\_spring08\\_newsletter.pdf](http://www.niscc.info/content/uploads/downloads/news/NISCC_spring08_newsletter.pdf)

Web link to the NISCC Newsletter Spring 2008 detailing the launch of the *Looking out From The Middle* research

[http://www.rqia.org.uk/what\\_we\\_do/public\\_participation/strengthening\\_user\\_involvement.cfm](http://www.rqia.org.uk/what_we_do/public_participation/strengthening_user_involvement.cfm)

The latter web link highlights the impact that the *Looking Out from The Middle* research has had on the development of the annual user involvement conference in Northern Ireland. Here, RQIA provides summaries of all of the conferences that have occurred since 2009.