



2009 User/Carer Conference

'Nothing about us without us' - Strengthening User Involvement in Northern Ireland, 5 February 2009

1. Introduction

- 1.1 The publication of "Looking Out from the Middle: User Involvement in Health and Social Care in Northern Ireland" (February 2008, www.scie.org.uk) a research initiative commissioned by Northern Ireland Health and Social Care Council (NISCC), the Regulation and Quality Improvement Authority (RQIA) and the Social Care Institute for Excellence (SCIE), inspired the three organisations to hold an annual event for users and carers.
- 1.2 On the 5 February 2009 the organisations hosted " 'Nothing about us without us' Strengthening User Involvement in Northern Ireland" as our first joint annual event for users and carers. At the event a range of presentations were made in the morning session in addition a number of workshops took place in the afternoon highlighting best practice initiatives as well as user and carer perspectives from across Northern Ireland.
- 1.3 Feedback from attendees was very positive. Many suggestions were made which we will take into account to ensure that next year's event will be a great success.

2. Outline of Presentations

- 2.1 Geraldine Campbell, Chair of the NISCC User and Carer Participation Group presented an overview of how the Group was established. The Group ensures the flow of fresh ideas and provides different opportunities for members to contribute and provide a user and carer perspective to challenge, influence and advise NISCC in carrying out its work.
- 2.2 Theresa Nixon, gave us an update on RQIA's progress against actions agreed in "Strengthening user involvement in Northern Ireland: a summary and action plan". This plan was developed by NISCC, RQIA and SCIE in response to the findings of "looking out from the Middle" ([link to this doc on SCIE website](#)) This includes the development of RQIA's Public Participation Strategy, communication with the public and training initiatives.

- 2.3 Ian Sutherland, a SCIE Board Trustee, outlined the Trustees role in finding out what works in social care, before translating it into guidance and then ensuring that it is implemented. SCIE is working to increase its presence in Northern Ireland. He highlighted that all SCIE resources are freely available on the organisation's website.
- 2.4 Pete Fleischmann, from SCIE spoke briefly about his own experiences as a user of mental health services and outlined SCIE's user involvement activities and structures. He said that three members of SCIE's Board have direct experience of using social care services. In addition, a number senior level SCIE employees have experience of using services. One third of SCIE key stakeholder network 'The Partners Council' must be made up from representatives of user or carer led organisations. A team of 4 full time staff manages SCIE's participation work.

3. Summary of Plenary Sessions

- 3.1 The plenary sessions were introduced by Joe Duffy from Queen's University and Brendan McKeever from a user background who reflected on the presentations. They commented on the progress that had been made since the publication of the "Looking out from the middle". They commended the organisations for making a real step towards meaningful engagement. They also welcomed the first joint user event as evidence that NISCC, RQIA and SCIE are committed to achieving meaningful user and carer involvement.
- 3.2 Marian Cinnamond, from the Alzheimer's Society introduced a DVD produced for the "Let Me Speak, Help Me Be Heard" dementia advocacy pilot where local people with Alzheimer's and their carers told of their experiences with the disease in an honest and touching way.
- 3.3 Jo Irvine, of VOYPIC explained how as a care experienced young person she gained confidence and helped young people in care have a voice during RQIA inspections. She gave details of how the training she received prepared her to take on the responsibility of the role of a peer reviewer and how she contributed to the final inspection report.
- 3.4 Martin Daly, a member of Life After Mental Health Problems (LAMP) shared his view from a service user perspective of how it feels to engage with health and social care (HSC) services. He also discussed the obstacles that he and others have faced in getting meaningful engagement and action at a time when it is most important during the journey to recovery. Martin also challenged the organisations to go beyond tokenism and offer real opportunities to engage at an early stage to help make a difference.

- 3.5 The Lobbying Activism and Research Group (LARG), concluded the plenary session with a thought provoking presentation detailing their experience of making stakeholder involvement a reality. The title of the presentation was "Work in Progress". This theme was used to describe their work and, the experience of how they established the group. They also gave us their personal and group achievements and highlighted ongoing tensions such as lack of resources and slow organisational change which continue to be a challenge to user involvement.

4. Workshop links

- 4.1 In the afternoon 6 parallel workshops took place covering a range of subjects.
- Let me speak - Help me be heard : Alzheimers Society
 - "Making User Involvement Real" - One Year On - Joe Duffy/Brendan McKeever
 - Voice of Young People in Care (VOYPIC)
 - Lobbying Activism and Research Group (LARG)
 - Co production a new model for user involvement (NISCC and SCIE)
 - Life after Mental Health Problems (LAMP) - Martin Daly
- 4.2 Following the workshops each group provided feedback and identified three action points that they would like to see progressed by the three organisations.

5. Closing Remarks

- 5.1 Dame Joan Harbison in her closing remarks highlighted the key messages discussed during the day. Dame Joan made a number of observations on the presentations and the key points made during the day. She concluded that while there are examples of good practice, that the three organisations should build on the success of the conference and find new ways to empower services users and their carers.
- 5.2 Next Steps in user and carer involvement for NISCC, RQIA and SCIE
- 5.3 Following the success of this user and carer event and using the feedback received , NISCC, RQIA and SCIE will:
- establish a Planning Committee for next year's event that will include user and carer representatives.
 - continue to develop actions agreed in "Strengthening user involvement in Northern Ireland: a summary and action plan" by:
 - holding regular participation group meetings
 - developing communication with users and carers
 - ensuring that the principles of user involvement are used when planning meetings and events

- continuing to develop training practice in user and carer participation
- reporting our user and carer activity on an annual basis

5.4 In addition to these initiatives all three organisations are progressing their user and carer involvement objectives through different aspects of their work. All three organisations are committed to highlighting best practice ideas and encouraging others within the Health and Social care family to offer users and carers more meaningful opportunities to engage.

5.5 RQIA's Theresa Nixon indicated that next year's event will demonstrate how close we come to working together to achieve the heights of excellence.