

2010 User/Carer Conference

Is Partnership working? 10 March 2010 - Event Summary

1. Background

- 1.1 In 2009 the Northern Ireland Health and Social Care Council (NISCC), the Regulation and Quality Improvement Authority (RQIA) and the Social Care Institute for Excellence (SCIE) held our first user and carer conference "From the Outside Looking In". This event followed the jointly organises launch of "Looking Out from the Middle: User Involvement in Health and Social Care in Northern Ireland" (February 2008, www.scie.org.uk) commissioned by the three organisations. This research highlighted the importance of showcasing user and carer involvement activity in health and social care to a wider audience.
- 1.2 This year we worked together again to host "Is Partnership Working?" at the Lagan Valley Island Civic Centre, Lisburn, on 10 March. Below is a summary of the event.

2. Overview of Is Partnership Working? Conference

2.1 Learning from 2009

- 2.1.1 The 2010 Conference was informed by feedback received from our user event in 2009. Participants had asked us to demonstrate that partnership working in NISCC, RQIA and SICE was more than a one-off event. We were also challenged to be more creative in the organisation of the event and to include the views from the people who matter, service users and carers.

2.2 Approach Taken to Organisation of 2010 Conference

- 2.2.1 The three host organisations agreed to take a different approach to organising the 2010 conference. We established an organising committee that included service users, carers and representatives NISCC, RQIA and SCIE. This group worked together to agree all aspects of the conference, from support services on the day and the varied range of workshops and how to organise these effectively. These included the choice of venue; catering; access issues; parking facilities; contributors and the types and timings of presentations.

2.2.2 Our aim was to provide an event that demonstrated partnership work in a variety of ways. Representative groups and individuals were encouraged to show their experience of partnership working, through presentations, information stands and workshops. In addition, the organising committee wanted to create an opportunity for people from all areas of health and social care (statutory, voluntary, independent and private) to meet, share and learn from the different approaches taken to partnership working across the sector.

3. Attendance

3.1 Over 170 delegates attended the conference. The audience included service users, carers, advocacy and voluntary sector representatives from across health and social care. These included mental health, physical, sensory and learning disability, people with long term conditions, older people and young people. Health and Social Care organisations were also present including Health and social care trusts, the Public Health Agency, the Health and Social Care Board and the Patient and Client Council. NISCC, RQIA and SCIE were also represented by board members, directors and senior managers.

4. Ministerial Visit

4.1 The Minister for Health Social Services and Public Safety, Michael McGimpsey, MLA, opened the event. He welcomed this initiative and commended the organisation the event, and recognised the importance of partnership working in the field in health and social care. During his visit the Minister also had the opportunity to speak with service users and carers.

5. Presentations

5.1 **Brendan McKeever** chaired the event on behalf of the organising committee and he provided a presentation from a personal perspective on how partnership should work. He also emphasised how important it is for health and social care organisations to listen to the views of services users and carers at all levels of decision-making. A series of presentations followed demonstrating involvement of service users by the NISCC, RQIA and SCIE.

5.2 **Maria Somerville** is a parent/carer of two disabled children, a member of the NISCC User Participation Group and a member of the Parent Carer Council on disability. She shared with us her very personal and moving experience of accessing social services as a carer and how this had changed her family's life. Maria also identified what staff need to be aware of in responding to the needs of families and disabled children.

- 5.3 **Philip O'Hara (RQIA) and Karen McAllister (VOYPIC)** presented an overview of how involving service users made a real impact on the RQIA's Review of Child Protection Services across Northern Ireland. The presentation highlighted the approach used in partnership with RQIA, VOYPIC, service users and health and social care trusts to provide feedback on how service users viewed the trust's delivery of child protection services.
- 5.4 **Pete Fleischmann and Shirley Ewart - Boyle (SCIE)** presented a short film demonstrating why user-led organisations are important. They also highlighted how this approach can help to facilitate service users in their empowerment, to become involved in decision-making and have a louder voice in society.
- 5.5 **Patricia Cushley (LARG)** provided an account of how the learning from the 2009 event informed the organising committee, the compromises that were made along the way and how she believed that the event was a true example of partnership working.

6. Workshops

- 6.1 Eleven workshops took place in the afternoon. The workshops held provided a range of examples of how partnership working has been used across health and social care as well as other settings to improve engagement with users and carers and to facilitate their voices being heard.

6.2 Patient Experience Reviews - Safeguarding the rights for detained patients: Carolyn Maxwell (RQIA) Paul McFall (Advocate)

The workshop discussed how working with services users, carers, providers and advocacy networks has helped shape and facilitate engagement with patients detained under the Mental Health (NI) Order 1986.

6.3 Participation - fit for purpose? Model of engagement used by NISCC: Rosemary McCarry, Geraldine Campell and Mark Bradley (NISCC)

This workshop looked at the NISCC model of participation and examined how it has engaged with users and carers to influence, advise and challenge the its work.

6.4 Service Framework for Respiratory Health and Well being - A work in progress: John O'Hagan (Asthma UK Northern Ireland), Dr Jenny Gingles (DHSSPS), Yvonne Monteith (Northern Ireland Chest Heart and Stroke Association), Mrs Kathleen Aylward (Service User)

The Service Framework for Respiratory Health and Well being was launched in December 2009. This is groundbreaking and innovative in terms of being the first document, anywhere in the UK, to set out standards for adults, children and young people with respiratory conditions.

Users and carers worked in partnership with the DHSSPS and clinicians to develop the asthma standards over a two-year period. This was developed using feedback from user and carer workshops, which were written up as submissions to the DHSSPS. The production of an easy-to-read version of the framework was one of the outcomes of this partnership work.

6.5 Is Partnership Working? Teresa Stewart, Gary Crozier, Sam Gibson and Rosemary Murray (Disabled Young People's Participation Project/ Sixth Sense Advocacy Group)

The workshop highlighted how the young people have based their participation on Article 12 of the United Nations Convention on the Rights of the Child (UNCRC). Every child and young person should have the right to have their say on issues that impact on their lives.

6.6 Public Engagement on Priorities for Action: Richard Dixon (Patient and Client Council)

A presentation on a project undertaken by the Patient and Client Council, this involved individual members of the public in an effort to influence the key departmental policy document priorities for action. It also enabled the participants to review the targets highlighted, and feedback on how the final report was used to influence / lobby government.

6.7 Working in Partnership the Wraparound way: Mary Duffin and Dr Brid Farrell (Wrap Around)

The all inclusive Wraparound scheme demonstrated partnership to develop new and distinctive ways of multi agency and multi professional working. The key focus of this group was to make a difference to the lives of children and young people with disabilities and their families/carers across the Southern Health and Social Trust was a key focus of this group.

The aim of Wraparound is to enable children with disabilities to have access to information, assessment and where appropriate, services which provide the social, health and educational support to maximise their potential to lead socially included lives.

6.8 Partnership Working in Cancer Services: Janis McCulla (NICaN) and Nicola Porter (GAIN)

This workshop outlined how partnership working is developing within cancer services, incorporating both statutory and voluntary sectors, through the Northern Ireland Cancer Network (NICaN). The session highlighted specific pieces of work which have been initiated and undertaken by members of the NICaN Patient and Public Involvement (PPI) Forum. These include a PPI-ed information audit and development of lung cancer support groups.

6.9 Seen and Heard: Lorraine Thompson (Include Youth)

This workshop highlighted the importance of listening to the views of at risk young people and how best to do this. It explored how their views can influence the development of services.

6.10 The Application of a Human Rights Approach to Inspection and Review of Health and Social Care by RQIA: Virginia McVea - Human Rights Advisor (RQIA)

This group explored the application of a human rights approach in the regulation of health and social care. They discussed how and when the principles of human rights can be applied and what effect this can have on the care received by patients and client's.

6.11 Working in Partnership with ARC to Provide a User Perspective on How RQIA Engage with service users during inspections: Garth Angew, Jim McBride (RQIA) and Orlagh Cassidy (ARC)

This workshop explored the relationship between RQIA and ARC in developing training and communications materials to help RQIA inspectors engage with service users/carers more effectively.

6.12 User-Led Organisations (ULOs); What are They and Do We Need More of Them? Pete Fleischmann (SCIE)

A user-led organisation (ULO) is an organisation that is run and controlled by people who use support services. They could be disabled people, mental health service users, older people or carers. A minimum of 50% of a ULO's management committee or board must consist of people who use support services. ULOs typically offer advocacy and peer support, advice and information about services and often work in partnership with other agencies to improve services.

Building on Pete's plenary talk about ULOs, this workshop explored issues around developing ULOs including:

- potential benefits of ULOs
- common barriers to developing ULOs

7 Information stands

7.1 A range of organisations and groups were invited to submit applications to host an information stand at the event to showcase examples of best practice in user and carer involvement. The information stands created opportunities for discussion and learning throughout the day. The following information stands were present at the event:

7.2 Looking Out from the Middle Research

This stand was hosted by Joe Duffy, Lecturer in Social Care, at QUB and some service users and carers who were involved in the original research that led to the establishment of this annual event.

7.3 Belfast Health and Social Care Trust (BHSCT) Carers Forum

This stand was hosted by members of the BHSCT Carers Forum and highlighted the work that the group undertakes within the trust. This stand provided an opportunity to discuss the impact and benefit of partnership working.

7.4 Young Peoples Participation Network

The Participation Network is supported by OFMDFM to help the public sector to engage effectively with children and young people in development and review of policy and services that impact on their lives. The Participation Network offers training, consultancy support, a signposting service and resources to central and local government.

7.5 Lobbying Activism and Research Group (LARG)

This stand was hosted by members of the group and provided information on the activity of this group of service users.

7.6 Equality 2000

A Dungannon-based voluntary organisation, run by disabled people, to promote equality of opportunity and full integration in society. It aims to deliver programmes of work which have a positive impact upon the lives of disabled people, either directly, or with others to improve access to services.

7.7 Asthma UK

This stand was hosted by Joan O'Hagan, Director of Asthma UK, and provided an overview of public involvement and awareness work undertaken by the organisation.

7.8 Royal National Institute for Deaf People (RNID)

This stand was hosted by staff from RNID and service users who will share their experience in partnership working and showcase a range of services offered.

7.9 Southern Health and Social Care Trust (SHSCT) PPI Project

This stand provided details of how the SHSCT had developed internal PPI structures. The stand was hosted by Carolyn Agnew, PPI lead, and a service user who shared their experiences of the trusts patient forum.

7.10 Voice of Young People in Care (VOYPiC)

This stand was hosted by staff from VOYPiC and showcased a range of their work including advocacy and participation projects. A VOYPiC representative made a presentation during the main event.

7.11 The Police Service of Northern Ireland (PSNI) Community Safety

This stand was hosted by PSNI staff and contained information on the community safety projects.

7.12 Northern Ireland Cancer Network (NICaN)

This stand was hosted by staff and cancer patients who promoted the work of the organisation and share their experience of partnership working. NICaN also hosted a workshop.

7.13 Include Youth

Staff and young people from the project shared information on how their projects works to promote the inclusion of young people in decision-making at a strategic level.

7.14 Patient and Client Council (PCC)

This stand was hosted by PCC staff and promoted the role of this organisation. Richard Dixon from the PCC also hosted a workshop during the day.

7.15 Social Care Institute for Excellence (SCIE)

The stand was manned by Pete Fleishmann, one of the event organisers and a range of publications relating to user and carer involvement were available.

7.16 Northern Ireland Social Care Council (NISCC)

Members of staff from NISCC hosted a stand which provides information about the range of work that is undertaken by the organisation. This included NISCC participation group activity, corporate information and registering of social care staff.

7.17 Regulation and Quality Improvement Authority (RQIA)

Members of staff from RQIA hosted a stand which provides information about the range of work that is undertaken by the organisation. This included, public participation activity, corporate information, inspection and review activity.

8. Feedback from the Event

- 8.1** Very positive feedback was received about the organisation of the event, venue and facilities. The presentations, workshops and information stands on the day also received positive feedback. Some people suggested that for next years we focus more on health related issues, service users rather than carers and consider including the PCC as a partner.