

Strengthening user involvement in Northern Ireland: a summary and action plan



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In response to *Looking out from the middle: user involvement in health and social care in Northern Ireland* by Joe Duffy and colleagues

“We need to see what we are being consulted about is making a difference ... we have to be in the middle looking out.” (service user)

“Users of services are in the best position to highlight what is good and poor about the services they receive.” (senior manager)

NISCC, RQIA, SCIE
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Foreword

The Northern Ireland Social Care Council (NISCC), the Regulation and Quality Improvement Authority (RQIA) and the Social Care Institute for Excellence (SCIE) commissioned this research with the aim of strengthening user involvement in Northern Ireland. We would like to take this opportunity to thank the research team, staff and all those who contributed in any way to this research. We are grateful for your time and input and hope that the actions that we take forward as a result of the research recommendations begin to deal with the themes that have been identified in the research.

The commissioning organisations see this research as a continuation of a process of participation, engagement and partnership with users and carers in our work in health and social care in Northern Ireland. The valuable contributions made during this research have provided NISCC, RQIA and SCIE with a useful insight into users' perspectives and what areas they feel are important to ensure more successful user involvement.

We are committed to putting user and carer involvement at the centre of our work and have included in this document a summary of the research and a joint action plan which details how we propose to progress the recommendations made in the research. The full

research report is available online at www.scie.org.uk

Introduction

Much work is being progressed in terms of user and carer involvement and many examples of good practice exist throughout Northern Ireland. NISCC, RQIA and SCIE wish to ensure that the role of users and carers is placed at the centre of work in health and social care in Northern Ireland. We already use a variety of methods to ensure that users and carers have a voice in the development of a high quality workforce, the inspection and review process and the gathering of knowledge about good practice. However, there is always more that can be done in this area and *Looking out from the middle* provides us with some valuable insights into how we can achieve better results from user involvement.

The commissioning organisations

Northern Ireland Social Care Council (NISCC)
NISCC was set up by the government to raise standards across the Northern Ireland social care workforce. It aims to achieve this objective by ensuring that all those people working in social work and social care and providing services to people in need are registered and work to high standards of quality.

Regulation and Quality Improvement Authority (RQIA)

RQIA is an independent organisation that is responsible for monitoring and inspecting both the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services.

Social Care Institute for Excellence (SCIE)

SCIE was also established by the government to improve social care services for adults and children in the UK. It aims to achieve this by identifying good practice and helping to ensure such practice becomes a part of everyday social care for people both receiving and providing services.

Each of the organisations have different roles. Both NISCC and RQIA have statutory regulatory roles and their remit is exclusive to Northern Ireland. SCIE is a London-based, UK-wide organisation with no physical presence in Northern Ireland and no regulatory powers. SCIE and NISCC are social care organisations, however, RQIA has responsibility for inspecting both health and social care services.

Looking out from the middle

At the time this research was commissioned we identified that there was a lack of published information surrounding user involvement in health and social care specific to Northern Ireland. NISCC, RQIA and SCIE all wish to

ensure that there is more effective user and carer participation in their organisations. The organisations recognised that carer networks and carer involvement have already been established in Northern Ireland.

The three organisations agreed that the involvement of service users may benefit from a broader, multiagency approach. To investigate this further, a consultation focusing on user involvement was commissioned by SCIE on behalf of all three organisations in October 2006. A team led by Joe Duffy from Queen's University, Belfast and including several user organisations were awarded the commission and work commenced in January 2007.

Summary

Project aims

Looking across health and social care services for children, young people and adults the project had four aims:

1. To provide a short summary of the history and principles of user involvement.
2. To describe the current situation in Northern Ireland.
3. To discuss a range of options for the further inclusion and participation of users in the work of NISCC, RQIA and SCIE.
4. To make recommendations to inform the development of a future strategy for user

involvement at a strategic level in Northern Ireland.

Method: how the team did the work

The team combined desk research (reading and thinking about user involvement) and interviews (speaking to people about user involvement). A total of 148 people were interviewed. All this information was collected together and analysed by the team.

A very broad range of service user and carer groups, organisations representing user interests and stakeholders with responsibility for service delivery in the health and social care sectors in Northern Ireland were interviewed.

It was important that minority ethnic and hard-to-reach/seldom heard groups' perspectives were covered. In addition consideration was given to the 1998 Northern Ireland Act (Section 75).

Findings: what the team found out

The findings from this consultation are presented as themes that commonly occurred in the interviews.

The following table lists the themes and shows how many times they were mentioned in the interviews.

Theme	Frequency in interviews
1. Communication	29
2. Values	23
3. Training	22
4. Practicalities	22
5. Knowledge of organisations	20
6. Support for a user group network	21
7. Feedback and Outcomes	17
8. Resources	13

Themes in brief

The content of each theme is outlined below. The text is supplemented with quotes from interviewees.

1. Communication

“Good communication skills is a must, training should be mandatory for all staff as good communication does not happen by chance, we all have to work at it.” (Residential Unit for Older People)

Respondents discussed communication in terms of the way organisations seeking user involvement communicate in a broad sense with the general public and structure their own working practices. This theme includes references to the skills and sensitivities which organisations need to take on board to ensure that all aspects of their business are accessible

to service users and carers. The consultation concluded that different user groups require different approaches to involvement.

2. Values

“It is a basic right of all human beings to have a say in any decision making that is going to affect their well-being/care or life in any way.”
(Residential Unit for Older People)

Effective user involvement and partnership working must be based on values such as respect, humanity, partnership, inclusion and a commitment to respecting the right to consultation and involvement. To be truly effective these values must be intergral to the way the three organisations engage users.

3. Training

“Anyone involved in a working organisation should have a detailed knowledge of that organisation ... this can be obtained by induction courses into the organisation.”
(Carers’ Group)

Training is important for everybody engaged in the process of user involvement. Although some users already felt well skilled in certain areas, many respondents felt that this should be a continuous process, important for both users as individuals wanting to build their own capacity and for staff in organisations.

4. Practicalities

“Organisations need to build relationships and allow trust to develop.” (Youth Justice Group)

User participation must be supported by keeping the emphasis on the practical considerations which help in making this work. Many examples of these were provided such as payments, timing of meetings, conduct of meetings, use of language, evaluation of user contributions, childcare and/or carer support and additional support before, during and after meetings.

5. Knowledge of Organisations

“Users of services are in the best position to highlight what is good and poor about the services they receive ... they also provide a unique insight into how services can be redesigned or improved.” (senior manager)

A recurrent theme from the many interviews was the fact that respondents knew very little about the work of NISCC, RQIA and SCIE. Nevertheless, what is encouraging was the willingness of groups and individuals to become fully involved in the work of such organisations, once they began to understand what they were about and who they were.

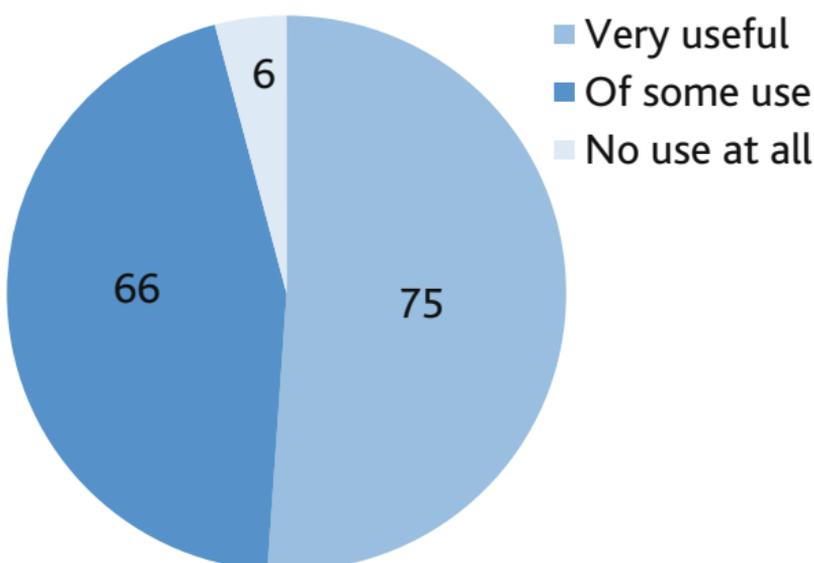
6. Support for a user group network

When posed with a question about the development of a national user network, most respondents felt that this was a good idea. A number of concerns were raised about how this

would realistically work. Critically it was the ownership of any network, by users themselves, which was highlighted on a number of occasions.

The chart below shows respondents' thoughts on how useful a Northern Ireland Network would be in terms of advancing issues around user involvement.

Development of a network



7. Feedback and outcomes

“Organisations need to provide feedback about how the views of service users have brought about changes.” (Mental Health Support/ Women’s Health Group)

A constant theme in the responses was the need for organisations to give feedback to individuals and groups with whom they have consulted as a real way of avoiding both *tokenism* and *consultation fatigue*. This emerged as a key

theme that had to be addressed, to ensure that negative experiences were overcome and future engagement assured.

8. Resources

“Larger organisations must invest in participation work, speak to experts, get guidance and share good practice....” (Young People’s Support Group)

This theme recognises that extra resources need to be committed by agencies to effectively support user involvement. In some cases this could mean having a designated staff member identified as a link person and having a budget associated with user engagement.

Action plan

The actions below are a list of steps that NISCC, RQIA and SCIE have agreed to progress in response to the recommendations made by *Looking out from the middle*.

Participation group

The three commissioning organisations will develop a participation group involving their participation staff and a cross-section of user groups. This group will support each organisation’s work on user involvement.

Improve communications to users and carers

Organisations will more clearly and actively communicate their roles and responsibilities to

service users and carers involved in their work and also to the wider community so there is clear understanding of what they do.

The three sponsoring organisations will work together to organise an annual information event to publicise their work in Northern Ireland and also highlight their interest in engaging and involving users' perspectives.

Principles for user involvement

The commissioning organisations will work with users and carers to develop a set of principles/ values for user involvement. These principles will be used to inform the continuing development of user involvement in each respective organisation.

Practicalities of involvement

Every consideration will be given to the issues raised by the research respondents to ensure that participation is more accessible.

Training

The three organisations will ensure that:

- training in the area of user involvement will be provided for all staff who are actively engaged in participation work¹

¹ Training for staff in user involvement issues currently occurs in both SCIE and NISCC.

- training is delivered in partnership with experienced user-led organisations and when appropriate coordinated across the three organisations
- the role of user participation is mainstreamed into the staff induction process²
- when appropriate, training for participation activity will be offered to service users and carers as a form of support and capacity building
- protocols are established for mentoring for new participation workers from more experienced staff members across the three agencies
- existing best practice in training is shared between the three organisations.

Annual reporting of user involvement activity

The chief executive of each commissioning organisation will report annually to their board about their progress and effectiveness in involving service users and any resources needed to develop this work in the next financial year.

User network

The DHSSPS (Department of Health, Social Services and Public Services) has established a stakeholder involvement network. They will be consulted about use of the network as a method of consultation.

² SCIE's induction procedure currently includes a meeting with the principal adviser in participation and the induction pack includes relevant policies.

Details of the stakeholder involvement network will be circulated to our users to provide them with an opportunity to become members.

Organisational champions for user involvement

A designated person will be appointed or nominated³ in each of the three commissioning organisations to coordinate the participation of service users. This person should be appointed at senior level with a specified budget and have an input at a strategic level in all these organisations.

Feedback

The three organisations will work together in agreeing best practice and protocols around giving feedback to users following participation and will also ensure that people are properly informed in an appropriate manner about the outcomes emerging from their participation. The three organisations should make this feedback available electronically on their websites.

³ SCIE already employ a principal advisor in participation and RQIA a public participation manager. In NISCC, the director of corporate services has responsibility for facilitating the Council's users' and carers' reference groups.

Acknowledgements

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3. The commissioners' reference group (Brendan Johnston, Chief Executive, NISCC; Teresa Nixon, Director of Operations and Chief Adviser of Social Work, RQIA; Pete Fleischmann, Principal Adviser Participation, SCIE; Margaret Shevlin, NISCC user and carer reference group)
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Looking out from the middle: user involvement in health and social care in Northern Ireland is available on our website.

All SCIE publications and resources are free.

This publication is available in an alternative format upon request.

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