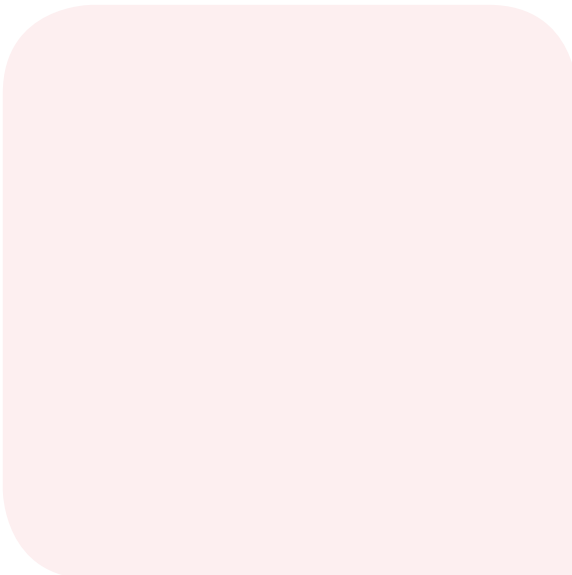
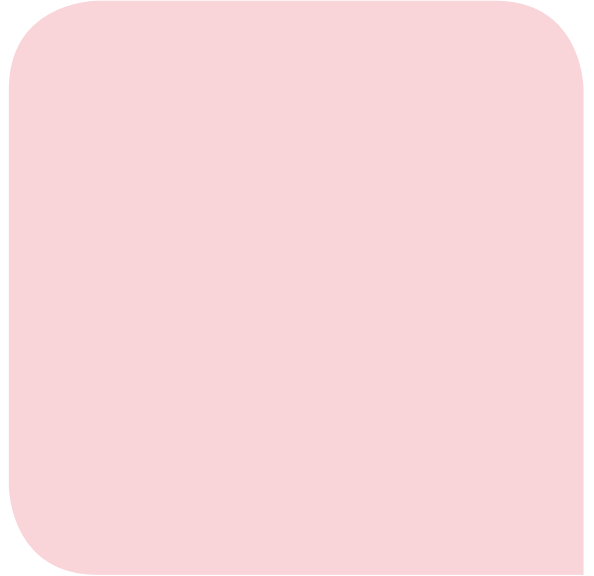


Looking out from the middle: User involvement in health and social care in Northern Ireland



Looking out from the middle: user involvement in health and social care in Northern Ireland

“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)

Joe Duffy

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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

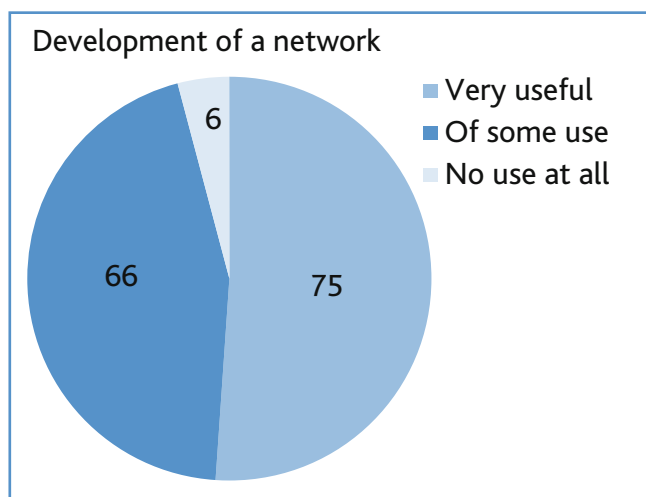
“Users of services are in the best position to highlight what is good and poor about the services they receive ... they also provide a unique insight into how services can be redesigned or improved.” (senior manager)

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.



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.

Recommendations

These recommendations are based on the findings from four different parts of this consultation. They therefore link directly to:

- the key messages from the literature on user involvement;
- the findings and themes from the interviews with all of the various stakeholders;
- examples of good practice emerging from the user groups and organisations consulted;
- examples of good practice evidenced from different parts of the statutory, private and voluntary sectors in Northern Ireland.

The recommendations are described and then followed up with further information that gives examples of how the recommendation can be followed through. Each recommendation presented will also be linked in with the particular theme that it is associated with in terms of its relationship to the consultation findings.

Recommendation 1

The three commissioning organisations should consider developing a participation group involving their participation staff and a cross-section of user groups. This group should focus on core aspects of each of the organisation's activities around user involvement.

Themes: Communication, Values, Training, Feedback and outcomes, Knowledge of organisations

Proposed actions for development

This group would support each organisation's work on user involvement. It could, for example, have a role in giving feedback on the written publications of each organisation, share examples of good practice in each organisation, develop evaluation and checklist tools, develop a certificated training programme around user involvement and plan communication strategies for each organisation including planning an annual information event. The membership of this group should be reviewed annually to ensure the continuing representativeness of a variety of user perspectives. This group should provide an annual report to the three chief executives of the sponsoring organisations for consideration in preparation of Recommendation 5 (see below).

Recommendation 2

Organisations should clearly and actively communicate their roles and responsibilities to service users and carers involved in their work and also in the wider community so there is clear understanding of what they do.

Themes: Communication, Values, Knowledge of organisations

Proposed actions for development

How organisations communicate with the public was felt to be very important in developing user involvement and in emphasising the importance of relationship and trust building as part of this. The evidence from the interviews clearly shows a lack of knowledge among the groups consulted about the three commissioning organisations. One way of helping with this could be for NISCC, RQIA and SCIE to consider how key staff members involved in participation work can spend dedicated time working with user groups in the community. This experience would be valuable in helping facilitate the participation of isolated/hard-to-reach groups. Providing such opportunities would also send a positive message to groups that organisations are committed to proactively seeking out seldom-heard groups. The database could be used as the basis for generating contacts with groups in the community. This is something that a participation group across all three organisations could help coordinate.

In terms of communicating with the public, the three sponsoring organisations could also work together to organise an annual information event to publicise their work in Northern Ireland and also highlight their interest in engaging and involving the user perspective in their work. Contacts from the database of service user/carer groups could again be used to attract a wide variety of groups to such an event.

Recommendation 3

Organisations seeking user involvement should commit themselves to an agreed set of principles/values that have been developed along with service users and carers.

Theme: Values

Proposed actions for development

The consultation stressed the importance of human and professional values such as respect, rights, humanity, individuality and partnership working as being central to working effectively with user interests. The three organisations could work together on agreeing a set of principles/values to guide their work on user involvement in Northern Ireland. This could be developed as a preliminary project by the participation group.

To ensure their practices consistently reflect such a value base, the sponsoring organisations should evaluate the experience of involvement from the perspective of both the user and staff members involved. Good practice in this area currently exists in both the Northern Health and Social Services Board (NHSSB) and the Eastern Health and Social Services Board (EHSSB) in Northern Ireland where checklists are completed to accompany each activity that has involved a user perspective. The three organisations should work together with service user representatives to develop an assessment/evaluative tool that could be used in each of their respective working environments. This would further reinforce the views expressed consistently by groups about their rights to participation and would also ensure that user involvement is perceived as a process instead of a series of one-off events.

Recommendation 4

Staff within each commissioning organisation should attend training on service user involvement. This should be commissioned from user-led groups and should also be available for service users and carers who feel that they would benefit from this.

Theme: Training

Proposed actions for development

Training in the area of user involvement should be compulsory for all staff in organisations who are actively engaged in participation work (training for staff in user involvement issues currently occurs in both SCIE and NISCC). Such training can be delivered in partnership with experienced user-led organisations. Staff induction is also an opportunity for ensuring that new staff understand the agencies' commitment to participation.

Training should also be offered to service users and carers as a form of support and capacity building. The three commissioning organisations could work together to share the contacts they have with user organisations when organising training. Another way for the commissioning organisations to work together is by offering mentoring for new participation workers from more experienced staff members across the three agencies. This would be a further method of promoting closer interagency working in this area.

Recommendation 5

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

Theme: Practicalities

Proposed actions for development

Organisations must continually consider and monitor the practical supports required as part of facilitating effective user involvement. To assist in this process, the three sponsoring organisations should use this report to consider ways of building practical supports for user involvement.

Recommendation 6

The findings from this small-scale study support the establishment of a network for user groups in Northern Ireland as one way in which such organisations can work together to build their capacity.

Theme: Support for a user group network

Proposed actions for development

There are a number of issues which need to be considered, in particular issues of funding and ownership of such a network and avoiding any duplication with other similar initiatives. (The *Draft framework for stakeholder involvement in health and social care* [DHSSPSNI, 2007a] describes current plans by Northern Ireland's Department of Health, Social Services and Public Safety [DHSSPSNI] to set up a stakeholder involvement regional network whose function would be to provide a platform for influencing strategic priorities and decision making in health and social care services across Northern Ireland.) The setting up of the participation group could act as an interim way in which the three organisations could work together to take forward the user participation agenda.

Recommendation 7

A designated person should be appointed in each of the three commissioning organisations to ensure the participation of service users in all aspects of their work.

Theme: Resources

Proposed actions for development

This person should be appointed at senior level with a specified and adequate budget and have an input at a strategic level in the organisation as a way of ensuring user involvement activities are reported on and evaluated. Such participation managers in each of the three organisations should examine ways in which their resources could be combined and information shared. (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.)

Recommendation 8

Service users and carers should be given feedback about the outcomes of any consultation they have been involved in.

Theme: Feedback and outcomes

Proposed actions for development

This is already established practice in many of Northern Ireland's HSSBs where feedback is monitored and audited through an established checklist covering this and other aspects of involvement. The three organisations should work together in agreeing best practice and protocols around giving feedback to users following participation and also about ensuring that people are properly informed in an appropriate manner about the outcomes emerging from their participation. The three organisations should make this available electronically on their websites.

1 Introduction

The three organisations sponsoring this consultation (NISCC, RQIA and SCIE), hereafter referred to as the 'commissioning organisations', were keen to ensure effective participation of users and carers in their work. To build on the progress they had already achieved, they were particularly interested in examining how service user and carer involvement might benefit from having a broader and more multiagency perspective. To investigate this further, a consultation focusing on user involvement was commissioned by SCIE on behalf of these three organisations in October 2006.

1.1 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 United Kingdom. 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.

1.2 Aims of the consultation

This consultation 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.

In addition the following objectives were also included:

1. To identify the number of service user organisations in Northern Ireland.
2. To explore and investigate the options for involving and improving service user involvement in Northern Ireland social care and health services at a strategic level.
3. To undertake the work in partnership with users.

4. To acknowledge and recommend options as to how social care agencies' need for service user involvement can be most effectively and efficiently delivered, while recognising the importance of the aspirations of users to develop and maintain their own autonomous voices.
5. To ensure that all relevant stakeholder groups are consulted including representatives of already existing user forums, individual users, individual carers, carers' organisations, senior managers, practitioners, social care educators and representatives of voluntary and statutory sectors.
6. To make recommendations regarding the development of a user/carer involvement strategy to be progressed by the three organisations and used to obtain the views of users and carers about the quality of care in relation to services purchased or provided on their behalf.

In response, this consultation was awarded to and completed by a project team from Northern Ireland involving service users, carers, agency representatives and academic staff from Queen's University, Belfast. Partnership working formed the basis of how this work was undertaken from beginning to end.

Care has been taken to ensure the report is written in a way that is understandable and accessible for everybody involved in the consultation and for the wider community who will have an interest in this work.

2 Methodology: how the consultation was carried out

2.1 Introduction

There are a variety of ways in which such consultations can take place. First, the team decided that we needed to produce both qualitative (information which expresses thoughts and ideas) and quantitative (information expressed through numbers) information. This meant ensuring that the interview was designed in a way that would allow such information to be expressed. Although there were some limitations to this approach, one of its strengths is that it helped us piece together a fairly reliable account of the views of the people who were involved in the consultation. This also enabled us to draw conclusions that reflected these opinions. The processes that we went through in order to do this work in many ways reflect the level of thought, preparation and sensitivity required when undertaking user involvement projects. However, giving attention to detail and preparation has resulted in a project that service users, carers and project team members have all seriously and genuinely committed to.

This section of the report takes the reader through the stages involved in undertaking the consultation.

2.2 Managing the project

- A *steering group* was established at the beginning of the project with membership from three service user/carer organisations and the project leader. This group met twice during the life of the work.
- The project leader and project team members also met with the *commissioners' reference group* on two occasions to report on the project. The project leader provided regular reports for these meetings.
- The *project team* consisted of service user/carer representatives and academic staff. This group met on a total of four occasions over the project and managed all the ongoing aspects of the consultation.

2.3 Reviewing the literature

The work was set in a broader context by providing a brief narrative review of the literature about the principles and history of user involvement. This review informed the selection of the sample, the content and design of the interview schedule and the identification of themes used in the analysis of materials. In addition, themes that emerged from the literature also supported the report's recommendations.

2.4 Designing a sample frame for the consultation

The original guidance provided by SCIE on behalf of the three organisations stated that a variety of individuals, groups and stakeholders from across the health and social care spectrum in Northern Ireland needed to be consulted in this work. In developing this further, the sponsoring organisations indicated that 26 such

consultations should take place. Stress was placed on the importance of hearing from service users and carers 'on the ground' in terms of 'what works' from their experiences of public bodies engaging successfully with users. What was very clear and motivating from the outset was that the three organisations supporting the consultation were genuinely keen to find out how to make user involvement work.

Mapping the extent of user involvement across Northern Ireland (project aim 2, see page 1) was a significant task, but nonetheless crucial in terms of helping the team identify who should be involved in the consultation. Two service user teams and the project leader completed this aspect of the work. A detailed preliminary database of service user and community organisations was constructed by:

- contacting district councils in each HSSB area in Northern Ireland
- telephone and email contact with relevant staff, including trust and board chief executives, equality managers and community development managers in the board areas with responsibility for user involvement initiatives
- internet research to identify groups through organisations' web-based directories/databases
- email inquiries through a Voluntary Organisations Forum (VOF)
- existing knowledge/networks from within the project team.

In this way, the team was able to produce a detailed *sample frame* (the total list of organisations from which a smaller number are selected for involvement in the consultation) from which 26 groups would be selected for the consultation.

2.5 Selecting the sample

The following criteria were then applied in relation to the selection of these groups:

- balanced representation of service user and carer interests
- the need for user-led, user-facilitated and representational groups
- inclusion of both health and social care aspects
- inclusion of minority ethnic perspectives
- representation of voluntary and statutory sector interests
- representation of 'hard-to-reach/seldom-heard' groups
- representation of a range of service user experiences, that is, physical disability, learning disability, mental health, children, older people, criminal justice
- consideration to the 1998 Northern Ireland Act (Section 75) inclusion of identified groupings and categories in terms of equality
- inclusion of both urban and rural perspectives.

The team then selected 26 groups that together represented all of these factors (see Appendix 2).

At the request of RQIA, we also agreed to survey the views of the three organisations commissioning the project, two private residential homes for older people and a relatives group. In addition, we interviewed three individuals from senior management, community development and health backgrounds, all of whom were active in promoting user involvement initiatives.

The total number of individuals who would therefore be involved in the 35 consultations was 148 ($n=148$, where n = the letter used in research to refer to *number*).

2.6 Ethical approval

The Social Research Ethics Committee (SREC) of the School of Sociology, Social Policy and Social Work, Queen's University, Belfast granted ethical approval for the consultation. However, the project leader advised the commissioners' reference group that this approval did not extend to consulting with individual service users and carers, which was a requirement in the original project instructions. We therefore agreed that the consultations would only take place with established groups.

2.7 Designing the interview

As this consultation would involve inquiry into people's thoughts, ideas and experiences on user involvement, the team felt that the best way of gathering this information would be through an interview containing a mixture of questions that would permit groups to openly express their views on the subject. It was also felt important, however, to include other types of focused questions that seemed to be important in the context of the existing research and policy literature that we examined. This helped us further explore views, thoughts and feelings about key issues identified with the aims of the project. The type of interview developed was called a *semi-structured interview*.

By its very nature, such an interview had to include *open questions*, where respondents could answer questions freely in their own words, and *closed questions*, where people had to choose from fixed options. Another feature of this interview was its inclusion of *prompts* after each question which were used to help respondents better understand a question if they had any difficulties.

Two service user teams and the project leader constructed the *interview schedule* (the term used to describe all of the questions in an interview and their instructions) (see Appendix 3). When the questions were agreed, these were then shared with other project team members to ensure they were accessible and easily understood given that a diversity of groups would be completing them. This also acted as a way of *piloting* (testing) the interview in terms of its suitability for accessing the information we were interested in. In addition to the interview which was designed to be easily understood, it also had to include questions directly relevant to the aims of the consultation. The interview had questions around skills necessary in the process of user involvement from both the user and host organisation's perspectives. In this way, again, the literature evidence had an important influence in the design of the interview.

2.8 Preparation for the interviews

The discussion in the literature around the history and principles of user involvement recognised that *consultation fatigue* was an issue that was very real for many groups. The project leader, therefore, made personal contact by telephone with all 26 groups identified for the sample to explain in detail what this consultation was about. In

some instances this contact was preceded by contact with a third party worker who was linked to a group. This was felt to be more sensitive than a telephone call coming from the project leader 'out of the blue'.

In this way, people had a chance to ask about the consultation and furthermore consult with other members of their organisation/group before committing themselves to participating. To help the groups in this process, relevant background information on the project (participant information form, see Appendix 4) was sent by email. Once group representatives contacted the project leader with a decision to be involved or not, which in some instances took a few weeks, a copy of the interview schedule and consent form (Appendix 3) were then forwarded. For some of the organisations consulted, this was their first experience of such involvement, so these sensitive preparations were necessary to ensure such people would not be deterred from being involved in similar future initiatives.

Project team members were then provided with a list of contact details for the organisations that had agreed to participate. Only one group did not take part in the consultation, meaning there was a total of 25 groups involved in this part of the work ($n=25$).

2.9 Conducting the interviews

The majority of the interviews took place face-to-face with the groups. When this was not possible, in a small number of cases groups sent through their completed interviews by email or post. As discussed above, the interview schedules were sent out in advance in order to facilitate plenty of time for consideration of responses to the questions.

Eight of the project team members were asked to complete several interviews each and to summarise the responses of the groups to the questions. The interviews tended to be very challenging for both the interviewers and the groups given the complexity and sensitivity of the subject matter being discussed. In most cases these lasted on average two hours each. The roles of the three organisations (NISCC, RQIA and SCIE) had to be explained in most instances, which was crucial in terms of allowing the groups to be informed enough to make their views heard; it also helped in the process of establishing trust. As said earlier, this was the first experience of involvement for some groups in a consultation like this, so flexibility and skills were needed on the part of the interviewer.

When the interviews were finished, each interviewer then completed a summary using a structure that had been designed by a service user project team member. This would assist with analysing the findings.

2.10 Scoping user involvement: the current situation in Northern Ireland

As previously mentioned, the approach to determining the nature of service user involvement in Northern Ireland was through making email contact with the chief executives of the 19 Health and Social Services Trusts (HSSTs) in Northern Ireland. In

addition to this, similar emails were sent to the chief executives of the four HSSBs, the four community development managers in each board area and senior staff in the voluntary sector.

This proved to be mostly successful in terms of generating further relevant contacts who were in turn able to provide useful information about both strategic and operational examples of user involvement across different sectors in Northern Ireland.

2.11 Analysing the findings from the consultation

There was a great deal of data collected in the process of this consultation, given that we carried out 35 consultations. It was therefore important that we designed a robust way of summarising key themes that emerged from the individual and group interviews. This also helped us to be more confident about the conclusions that were drawn from the consultation process.

Four members of the research team, consisting of two user researchers and two academic team members were chosen to review the *data* (the term used in research to describe the information collected) from the completed interviews. All four had previous experience in interviewing service users and analysing such data. It was decided that the information collected from each consultation would be distributed to each of these project members, with the proviso that they would not be examining their own interview data. Prior to the examination of the data, review members spent time agreeing the process. A schedule was devised which asked the reviewers to identify the frequency of key words and themes that were recorded on the interview forms. This approach is sometimes described as content analysis, where recurring ideas or views that emerge from interviews cannot just be quantified, but also connections made between a range of views. Although the interview schedule partly directed respondents to answer questions that were deemed to be of importance in this field, it also allowed respondents to concentrate on particular themes if they so wished, or sometimes to move away and develop other views on the issues being asked about.

Once the reviewers had spent some time independently examining each of their batch of interview schedules, they met to agree what they viewed were the important themes which had emerged, both in terms of frequency, but also the detail and emphasis given to these themes by respondents. At this stage of analysis it was possible to merge a number of similar themes to help manage the data. As said earlier, we believe that the selection of respondents, the design of the schedules and interview process, alongside the way that the data was analysed, allowed us to be confident that the themes which emerged were broadly representative of the views expressed by respondents. It is also possible, therefore, to draw conclusions, bearing in mind the limitations of the project discussed below, about the strengths and weaknesses of policy and practice in this important area of service user and carer involvement.

2.12 Discussion of themes and forming recommendations

The report presents each theme separately with relevant inclusion and reference to the consultees' responses. Where appropriate, direct quotes are used to highlight and support the theme under discussion. In this way, the recommendations associated with the consultation can be directly traced to the findings accompanying each particular theme. The recommendations for the consultation therefore relate mostly to what we were told in the interviews. There were also examples of good practice in the consultation that the team members felt should be summarised and highlighted. These are presented in a later section of the report and can be used by the three sponsoring organisations to support their implementation of the recommendations. These are also described in terms of their relationship to the overarching themes that have informed the recommendations. Furthermore, the brief narrative summarising the history and principles of user involvement also reached important conclusions. Again these should be seen as supporting the key overall findings from the consultation.

The recommendations of the report have been presented in this way, following consultation with all of the project team in light of *all* of the findings. Service user and research colleagues and the other academic staff team members have all equally influenced the wording of these recommendations.

2.13 Limitations of the methodology

Given the time and resources available to the project team there are inevitable limitations to such a consultation. Although a thorough attempt was made to make the selection of respondents as representative as possible across a range of sectors and service user and carer groups, there may be other views on this subject which were not captured. The mixed method approach used allowed us to capture the important views of a wide range of respondents. It is important to acknowledge in any such interview process that there is potential for interviewer bias. However, all interviews and focus groups were carried out by experienced researchers and practitioners in this field, which may have reduced this possibility. We believe that the fact that service user and carer groups were involved in the design and implementation of the project strengthens the outcomes and recommendations.

The consultation also took place in the aftermath of a substantial review of the way health and social care services were organised in Northern Ireland. A Review of Public Administration (RPA) was launched by the Northern Ireland Executive in June 2002 and concluded in March 2006 following a comprehensive examination of the arrangements for the administration and delivery of all public services in Northern Ireland. The review included almost 150 public bodies, such as Northern Ireland's 26 district councils, the HSSBs and HSSTs, the five Education and Library Boards and about 100 other organisations.

In November 2005, the Secretary of State announced the final outcome of the review in two parts. First, he announced final decisions on the future of local government, education and health and social services structures and in March 2006 he announced decisions on the remaining public bodies (www.rpani.gov.uk/index/

rpa-reviewresearch-decisions/background.htm). As a result, since April 2007, there are now five new Health and Social Care Trusts in Northern Ireland replacing the previous 19.

Many people and groups are therefore to be commended for sustaining a commitment to the project at a time of adjusting to such significant change.

3 History and principles of user involvement

In looking at the historical aspects and principles of user involvement in the literature, the project team members felt that this had to help inform other parts of the consultation. In this way, for example, the team felt it important to include the views of *hard-to-reach/seldom-heard* groups in the consultation as the literature was referring to their under-representation. The inclusion of questions concerning *skills* needed by both staff and users in the area of user involvement had also emerged directly from previous published work in this area and was therefore included as a question in the interviews. The emphasis in this short narrative account is therefore on relevant publications from mostly over the past decade; significant earlier publications cannot be overlooked, however. We also felt it was important for this account to chart the development of user involvement across the UK in terms of important law and policy that has helped shape and direct this.

3.1 Introduction

In Northern Ireland, government, employers and professionals now share a common commitment to promoting service user involvement in all aspects of the planning, delivery and monitoring of health and social services, including the education and training of staff. However, service user involvement in health and social services in Northern Ireland is a relatively new development. While much progress has been achieved there is still considerable uncertainty about the nature and impact of service user involvement and how this might be developed in future.

In the UK some writers have argued that service user involvement in the planning and delivery of services has now become central to the government's aim to modernise health and social care (DHSSPSNI, 2004a, 2007b; Farrell, 2004). However, others point out that although policy makers' efforts to encourage service user participation have been well intended, the extent to which meaningful involvement has been achieved is questionable.

A number of significant issues continue to present challenges in achieving meaningful user involvement. These include concerns about selection (CPPIH, 2004: see www.cppih.org), representativeness (Hasler, 2003), consultation fatigue (Olsen et al, 1997), tokenism (Chambers et al, 2003); reimbursement/payment (Hasler, 2003; Levin, 2004; DHSSPSNI, 2006a; Duffy, 2006) and support/training (Hasler, 2003; Levin, 2004).

This report begins with a review of how agency policy around service user involvement has developed locally, nationally and internationally. This is followed by an exploration of the different definitions of service user involvement and a discussion of the ways this occurs in Northern Ireland. Finally, we highlight the key issues and messages that have emerged from the research and literature and identify a number of areas in which service user involvement could be further developed in Northern Ireland based on this evidence.

3.2 Overview of national and local legislation and policy on service user involvement

The drive towards increased user and carer involvement in both health and social service provision has become well embedded in legislation and policy both in Northern Ireland and the rest of the UK over the past 20 years (DH, 1997). The 1998 Northern Ireland Act was particularly important in the legislative requirements it laid down to ensure that certain categories of individuals and groups were not discriminated against by public bodies in their delivery of services. This, along with other key initiatives around involving user perspectives, is presented as a timeline in Appendix 4. What is broadly apparent from examining the range of policies and laws introduced since the late 1990s until presently is that user involvement as a concept is well and truly embedded in key public policy areas across the UK, and is now referred to as the government's *personalisation agenda*.^{*} What has been slow to develop, however, is guidance on how user involvement can be put into practice. Internationally, the drive for user involvement within healthcare has its origins in *Primary health care*, published by the World Health Organization (WHO) in 1978, which argued for service users and the general public being involved in both the planning and delivery of healthcare services. Since then, service user involvement has become important not just in relation to its impact on services but also as a way of empowering and building the capacity of service users themselves. For example, Lorenz (1994) describes social movements such as Italy's *Psichiatria Democratica*, which 'championed client participation and self direction as both a therapeutic and a political goal' (p 108). However, while most European governments have adopted the philosophy of user involvement, both the pace and progress of involvement has been limited (Cook and Klein, 2005).

3.3 User participation: what does it mean?

The language around user involvement has a well-established history dating back to its first description as the *client perspective* in social work literature (Meyer and Timms, 1970). Since then, a variety of terminology, often used interchangeably, has been applied to the subject, including service user, user, expert by experience, customer and consumer.

There are also difficulties surrounding what service user involvement actually means in practice. A more detailed discussion and description of the terms used in this report is further developed in Appendix 1. For the purpose of this report, however, the terms 'service user/user' will be used to describe people who have experience of both receiving and the potential for influencing health and social care services. The term 'carer' refers to people who care for those in receipt of such services. While the terms 'service user' and 'carer' have their own distinct identity, the report will

* Peter Beresford, OBE, Chair of Shaping Our Lives and Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University, was writing a short article on the inclusion of service users and carers in social work education for *Compass (2008) – the complete guide to social work and social care*, where he makes this reference on page 28.

also use the term 'user involvement' in the interests of brevity to broadly cover the interests of both terms. This is not, therefore, meant in any way to take away from the unique understanding of these definitions.

3.4 Challenges and opportunities for developing service user involvement in Northern Ireland

Service users in Northern Ireland face a particular set of problems, from general inadequacies in services and resources, relative to other parts of the UK, to the additional burden of living in a divided society characterised by high levels of poverty and social deprivation (DHSSPSNI, 2004a).

Since the 1998 Northern Ireland Act, successive administrations have been committed to pursuing policies of equal opportunities, social inclusion and community development (Fay et al, 1999). The new political environment in Northern Ireland has already given a fresh impetus to promoting the involvement of service users in the planning and delivery of services.

However, as elsewhere in the UK, the development of service user involvement in Northern Ireland has been uneven across agencies, ranging from passive consultation exercises, to arrangements in which users are actively in charge of their own resources (Hirschman, 1970; Peck et al, 2002). Some areas of service user involvement, such as with people with physical disability, appear to be relatively well advanced while other areas, such as in the field of criminal justice, are markedly underdeveloped. Nevertheless, in Northern Ireland, the topic of service user/carer involvement in a variety of areas of public life and policy has increasingly become the focus of research and analysis by both academics and agency partners in collaboration with service users themselves (Campbell and Wilson, 2004; Conn and Wilson, 2005; Conn, 2006; Duffy, 2006; Wilson and Daly, 2007).

In addition, some service users and carers have broken new ground in writing about their experiences. For example, McKeever (2000a, 2000b, 2001a, 2001b, 2002, 2006) has written extensively on user involvement issues and identified the key ingredients for effective participation. These include the need to ensure that user involvement is not *tokenistic*, that it must reflect the *lived experience* of those who use services and must be real *partnership working* with those who plan and deliver services. McKeever also emphasises the importance of the *values* that should underpin user involvement including the importance of being listened to and heard, mutual respect, valuing people, receiving *feedback* and ensuring appropriate action and delivering *results*.

3.5 Beyond tokenism: mainstreaming service user involvement

There have been few large-scale research studies of the impact of service user involvement in the UK. Existing research tends to suggest that the growth of service user involvement has encountered many difficulties ranging from opposition by health and social services professionals to insufficient and insecure funding (Bowl, 1996; Barker et al, 1997). There are conflicting views as to what extent service user involvement has moved beyond tokenism to genuine power sharing or how effective

it has been in influencing health, social policy and social services developments (Bowl, 1996; Barnes and Shardlow, 1997).

Service user involvement therefore continues to present significant challenges to the dominance of professional and managerial hierarchies and traditional approaches to service provision (Bowl, 1996; Pilgrim and Waldron, 1998). It has been suggested that participation in traditional committee-style structures, in which much of the work of health and social services organisations occurs, is not always conducive to facilitating service user involvement (Peck et al, 2002). Such environments tend to reinforce existing power inequalities and give more importance to professional knowledge and expertise over the actual experience of service users (Pilgrim and Waldron, 1998; Bamford, 2005).

Nevertheless, service user involvement has increasingly been viewed as an essential component of the planning, delivery and monitoring of health and social services provision in Northern Ireland (DHSSPSNI, 2007b). However, at present there is no regional infrastructure in Northern Ireland with responsibility for promoting the strategic development of service user involvement.

3.5.1 The way forward

Clearly, considerable work remains to be done to ensure that service user involvement becomes an essential and meaningful component of the planning and delivery of health and social services. The new DHSSPSNI guidelines for service user involvement (2007b) represent, however, an important strategic step forward in helping to ensure it becomes an organic aspect of agency culture and practice.

It is also hoped that the establishment of the new Northern Ireland Assembly will provide further impetus and resources essential to securing the mainstreaming and further development of service user involvement within all health and social services organisations.

This short narrative review of the history and principles around user involvement has suggested a number of key areas in which service user involvement needs to be further developed. The following key points have therefore emerged as important to this consultation and have informed both the types of questions we asked and the way the project team approached the interviews. Furthermore, many of these points strongly echo the findings from our primary research for the consultation and alongside these they have ultimately informed and supported both our conclusions and recommendations for the three sponsoring organisations.

Key summary points from this narrative

- It is important to directly involve service users in ongoing discussions about how they believe their involvement and participation in health and social services can be promoted.
- There is value in considering the development of a regional infrastructure to support and facilitate service user involvement across the range of health and social services organisations and programmes of care.
- A secure funding base is necessary for established and emerging service user organisations in order to promote their independence and encourage self-advocacy.
- More creative ways of involving service users in the planning, delivery and monitoring of health and social services, alongside existing traditional committee-style structures, should be developed.
- There is a need to develop agreed definitions of service user involvement.
- There is a need to conduct more in-depth research on the impact of service user involvement in the planning, delivery and monitoring of health and social services in Northern Ireland.

4 The current situation in Northern Ireland

This section includes some examples of current practice in user involvement in the statutory and voluntary sectors in Northern Ireland.

During the period of the consultation, Northern Ireland's four HSSBs and HSSTs were re-structured. As a result, on 1 April 2007, five new trusts replaced the previous 19. Having said this, the four existing boards are to remain in place pending further consideration by the Northern Ireland Executive about the shape of future reforms.

4.1 Introduction

Service user and carer involvement is well embedded in the fabric of Northern Ireland's HSSBs and their associated HSSTs. Policies and procedures are in place in all of these in terms of driving forward the initiatives. For its part, the voluntary sector also has examples of attempts to advance user involvement in a way that also aims to produce opportunities for networking among groups.

4.2 Northern Health and Social Services Board (NHSSB)

NHSSB has developed a policy for public involvement reflecting its commitment to developing partnerships with the public when planning and developing services (NHSSB, 2001). The views of service users are sought using a range of methods, including questionnaires and user/carer/staff focus groups. The board introduced a more structured way of complementing this approach to user involvement by establishing a *public panel* in 2003. The panel provides a pool of people who are available to contact when the opportunity arises for public involvement. In addition, the NHSSB has developed a *checklist* to accompany its user involvement initiatives, which is intended to ensure that its approach to user involvement is standardised and supportive. This checklist covers areas such as:

- being clear about the purpose of involvement from the outset
- considering the most suitable method of involvement
- induction and training as a form of support to users
- resources, payment and practical issues
- considering preparation before a meeting, support during this and feedback about outcomes
- evaluating the experience of involvement from the user perspective.

4.3 Western Health and Social Services Board (WHSSB)

In March 2005, WHSSB launched its guide for public involvement and user engagement. This provides some basic insight into the meaning of public involvement and user engagement, the rationale for this and the benefits to both users and service providers. It also provides guidance on a range of tools that can be used, and gives further sources of information and guidance for those about to engage in user involvement initiatives.

In addition to this the WHSSB has established a user involvement coordination subgroup that is facilitated by five strategically placed community networks with their own budget across its geography. The board works with these networks to organise public meetings/focus group sessions in localised areas to present the issues and to hear the views of the local people on a variety of services.

4.4 Eastern Health and Social Services Board (EHSSB)

The EHSSB has a public participation strategy that has helped shape and inform user participation activities at both board and trust level (Manning, 2004). One of the largest former trusts in this board has created a *patient forum* that encourages patients to assist the trust in meeting its commitment to user involvement. This forum is asked to comment on projects as they arise and a policy document contains positive practice on user involvement, such as:

- *preparing* for user involvement in terms of considering the purpose of the consultation and how it is to be properly managed
- considering what needs to happen *at the event* in terms of supporting users
- ensuring that participants receive *feedback* in terms of the *outcomes* of the actual consultation itself.

4.5 Southern Health and Social Services Board (SHSSB)

SHSSB is also engaged in a wide variety of initiatives on user involvement and at the time of writing was drafting a user involvement policy (2007). This policy includes a set of principles for user involvement and develops ideas for involvement at five levels, from individual to management group level. In addition a comprehensive overview of user involvement initiatives was completed in the Newry and Mourne Trust area which mapped examples of involvement in different programmes of care in the trust using the five levels of involvement that were used in the board policy previously mentioned (Level 1: individual; Level 2: family/interest group/community group; Level 3: issue specific; Level 4: planning team level; Level 5: management group). This activity uncovered a variety of innovative user participation initiatives occurring within this particular trust area. Other trusts within the SHSSB are equally active in this area, engaging with a variety of user groups through user forums across programmes of care such as physical and sensory disability, family and child care and elderly healthcare and mental health. In addition there are a number of active health-related user and carers groups in the board area.

4.6 Service user involvement in the voluntary sector

The research for this consultation also involved making contact with key parts of the voluntary sector in Northern Ireland. The following are some examples of resources that have been shared with the project team.

Northern Ireland Cancer Network (NICAN)

describes itself as:

... an inclusive partnership of organisations working collaboratively with service user representatives to secure the effective planning, delivery and monitoring of cancer services. The aim of the Cancer Network is to promote equitable provision of high quality standards driven services that are clinically effective and patient focused. (www.nican.n-i.nhs.uk)

The network is very committed to the principles of user involvement and a number of user groups and forums have been established that reflect this.

Community Development and Health Network

This network describes itself as a 'member-led organisation which aims to make a significant contribution to ending health inequalities using a community development approach' (www.cdhn.org). In addition this network is active in influencing policy by encouraging policy makers to adopt community development approaches to addressing health inequalities. In doing so, it maintains close links with other community groups in pursuing its overall aim to reduce health inequalities in Northern Ireland.

Other

Other parts of the voluntary sector promote similar methods of maintaining links with other groups. Disability Action, for example, a large umbrella group representing the interests of people with disabilities, includes a detailed directory of groups across Northern Ireland on its website (www.disabilityaction.org/). Similarly, Include Youth, an organisation that works to enhance services for vulnerable young people at risk of entering the care or criminal justice systems, has a directory of organisations working with or on behalf of children and young people (www.includeyouth.org/). Other organisations, such as Age Concern and Mencap also have directories and networks of groups that are associated with older people and people who have learning disabilities.

5 Numbers of service user organisations in Northern Ireland

One of the objectives of the project was to establish the number of service user organisations in Northern Ireland. The project used the following definition of a service user organisation: a service user organisation is one in which over 50% of the members of the group's governing body are people who have direct experience of using social care or health services.

This task proved to be much more complex and difficult than anticipated. Health and social care services in Northern Ireland are undergoing a period of significant change. In addition many service user organisations are small, informal, poorly resourced and some are quite transitory. In addition the data has been collected from diverse sources and it is a complicated task to establish definitively the governance arrangements of a wide range of organisations.

As described in the methodology, a spreadsheet was completed to map the numbers of community and service user organisations in Northern Ireland. It is a compendium of information gathered from contacts from across Northern Ireland. The spreadsheet of community and user organisations is work in progress and will require further work and updating on a regular basis.

Given the limitations stated above it is difficult to reliably establish the number of service user organisations in Northern Ireland. However, an informed estimate is that currently there are between 30 to 40 service user organisations in Northern Ireland.

6 Findings

6.1 Analysis of the themes

This section examines and expands on the themes in more detail. Each theme is presented with quotes that are associated with and support the theme. In this way the reader is informed about what 'people on the ground' think is important in terms of user involvement.

These themes, along with the amount of times they emerged in the course of all the interviews, are described in Table 1.

Table 1: Frequency of interview themes

| 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 | 13 |
| 8. Resources | 17 |

6.2 Theme 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)

The interviews generated a broad range of suggestions to inform organisations generally about the importance of how to communicate with service users/carers in a practical and skilled manner. Furthermore, there were ideas as to how service providers might communicate with communities and groups at grass-roots level. Suggestions were also made about how organisations might need to address the very nature of how they worked to ensure that barriers to user involvement were removed.

6.2.1 Organisations communicating with service users and carers

"An ability to listen and accept that they don't always know best is important."
(Disabled Young People's Group)

“Have common sense and be a good listener.” (Older People Group)

The need to avoid the use of jargon in communication was a point repeatedly made in the interviews. Also the need to make sure that information used by organisations when working with users was accessible and appropriate to their particular needs was stressed. For example, an organisation representing the interests of young carers states: “Professionals should stop using jargon to care receivers”.

This interviewee developed this further by stating that skills were also needed by staff such as: “... good communication and listening skills to understand carers are partners not resources”.

The importance of the personal qualities of staff engaged in this work was also mentioned, in particular the need to be “friendly and approachable” (Mental Health Advocacy Group).

On the issue of accessibility, several groups suggested that organisations should consider presenting information in alternative formats for people with visual impairments and learning disabilities.

The ability for organisations to utilise and appreciate the *skill mix* that the user perspective brings was also felt to be important, as well as being able to “take criticism constructively” (Carers’ Group). A group representing young people also made a similar point around the importance of acceptance:

“Depth is vital ... the need to build relationships with young people ... we must not judge them or react too quickly to their presenting behaviour or be offended by it ... but see behind it ... get to the person with their problems ... get to empathy.”

In contrast, however, another group representing older people’s issues felt that there needed to be an “an appreciation that older people don’t like to complain”, and therefore an organisation had to adopt a culture that encouraged “real consultation” (Older People’s Group). The importance for organisations to carefully consider how this culture could be created was noted by another group who felt that “Informality is important, language is important, it has to be accessible” (Health Support Group).

This notion of informality was also made by two groups representing the interests of young people, who both felt that formality could obstruct effective involvement with young people: “they need to think about their clothes and be person-centred”; “there is a distance conservative culture in Northern Ireland, for example, suits, this creates blocks”.

Another group representing the interests of people with learning disabilities felt that a host of skills were needed by organisations involved in consultations with users: “Respect, listening, communication, including alternative methods of communication, community development skills ... and good negotiation skills are all needed”.

The importance of *how* people communicate was also seen as important to several groups. The following quote poignantly emphasises this for one such group: “body language and attitudes are often such that you feel excluded even when you are in the room” (Service User Group).

6.2.2 Skills needed by users

Many groups felt the experience of being a service user/carer enabled many people to feel confident about engaging with organisations seeking their involvement. However, there were equally some constructive suggestions made about the part that skills could play in helping users to maximise the benefits of their involvement, albeit if they had the interest to be involved in the first place.

For example, a support group for young people with disabilities felt that service users had to show a willingness to reassure staff in organisations that they did not want to make their life more difficult; rather that they wished to work in partnership for the common good. This group also added that in doing so, users needed the skills to recognise that they represented the wider disability sector and not just themselves. A support group for older people made a similar point about objectivity, saying that: “we need to know how to answer questions in a specific way which avoids the temptation to go into our own personal accounts”.

The confidence needed to participate in this way was, however, an issue for a number of groups. Related to developing such confidence was the part that organisations could play in supporting and empowering such contributions in a way that valued the skills and experience that users brought to the table.

6.2.3 Organisations communicating with the public

“Organisations don’t always give you the information you need to influence them.”
(Disability Advocacy Group)

The idea that such organisations should communicate directly with communities and ‘hard-to-reach’ groups was expressed by several groups as a way of demonstrating a real commitment to partnership working with such users. “Senior managers need to come out to see young people in the community” was a call made by a support group for young people and also by a group representing older people’s interests:

“There is no substitute to reaching out to users/carers in person.” (staff member, Residential Unit for Older People)

The notion of secondment to community groups was also a suggestion in this regard where staff in organisations seeking user participation could spend time working with users on their own ground. This was felt to be one way in which people could be helped in their engagement with organisations.

6.2.4 Possible barriers/obstacles to effective communication

“The mindset within the organisation needs to change.” (Learning Disability Advocacy Group)

“The whole organisation has to be ready to change.” (Traveller Women’s Group)

“Staff attitude is critical to success ... they need to be convinced this is useful.” (Carers’ Group)

These opening quotes highlight some of the challenges facing larger organisations seeking to embrace change through involving a user perspective. What this means is that people have to fully commit and believe in the value of pursuing this. In other words, this has to be seen as a *way of thinking* that everybody in the organisation signs up to. By thinking and acting in this way, it may then become possible to achieve quality in partnership working with users that promotes “substance” (Service User Group) and avoids tokenism.

However, this consultation cautions that larger organisations may struggle to achieve this given the complicated way many of them are structured, as the following quote implies: “the smaller the organisation the more personal touch – the larger the more distant and bureaucratic...” (Advocacy Group for Physical Disability).

This difficulty is challenged by staff with experience of working in larger organisations: “While the organisations are large, this presents opportunities and not necessarily barriers – it should be easier to get meaningful and consistent engagement provided the trust board want it to happen”. Another respondent with experience of working in a large health and social care setting made a similar point: “Prior to RPA [Review of Public Administration] our organisation was one of the largest in Northern Ireland and we achieved service user and carer involvement – it just needs commitment from the top and a willingness from staff to try” (senior trust staff member).

The challenge is therefore to move from a *way of thinking* to a *way of working*. The following quote urges us to think about how staff need to approach this work: “Staff need the attitude and humility to accept that they are not the experts but ... are unlocking the ideas and potential from the real experts ie users” (senior manager). What is also important in this, however, is the self-awareness that organisations need to have about their user involvement activities.

For such organisations to have confidence in their positive claims about user involvement, they need to ensure they are checking with service users and carers about whether their involvement actually is effective. To avoid doing this, there is the real danger that users will perceive their involvement as tokenistic and a gap will remain around perceptions of user involvement from both the user and the organisation’s perspectives.

6.3 Theme 2: Values

“Put yourself in the service user’s/carer’s shoes and treat them as you would like to be treated.” (manager, Private Residential Unit for Older People)

A range of comments similar to the above emerged from the consultation, highlighting the importance of agencies approaching user involvement with a commitment to values such as partnership, humanity, respecting people, treating people as individuals, not making judgements, avoiding stereotyping etc.

The notion of partnership also occurs as important: “It is important that carers are given respect and are also listened to ... as equal partners ... not us and them” (Carers’ Group). Other groups mention the importance of “feeling valued, never feeling silly and feeling important, where everything we say is worth listening to” (Relatives’ Group). Another group said, however, that their experience of user involvement had been negative and they were unwilling to ask questions at such times “for fear of looking stupid” (Service User Group).

The issue of working in partnership with children and young people was also felt to be important. One group of parents of children with health-related problems, for example, felt that professionals often overlooked the needs/interests of their children and instead addressed issues through the parents. A group of young people with disabilities challenge this: “our parents’ views are not necessarily our views ... we know what we need”.

Another group representing young people made a similar point about how agencies need to guard against labelling young people: “Young people’s behaviour can be challenging to professionals ... it is here that professionals need to develop their skills base ... acceptance and being non-judgemental is critically important ... respect is the key”.

The notion of honesty as an important value was also mentioned as being important to user involvement. For example, a group representing the interests of older people commented: “organisations need to tell us what they can do instead of what they can’t do”. A similar point was made by a group representing the interests of children: “be honest about what the agency can deliver”. A group representing the interests of people with learning disabilities also commented, by way of contrast, that agencies must be “clear about what people who use services/carers can/cannot change and what their role is”.

The issue of rights also appears as being important to the extent that people now have rights around consultation due to the current statutory and policy requirements in relation to consulting service users in Northern Ireland, as the following quote suggests: “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). A mental health support group, however, stated that the experience of being a service user was enough to give a person the right to be consulted and

to influence how services were developed, implying that such experience was more important than the presence of laws mandating involvement.

The notion of what many groups described as *humanity* was also mentioned as a core way in which an organisation could convey respect and courtesy in the process of engaging with service users. Examples provided accompanying this were about how staff in organisations needed to show genuine interest, friendliness and approachability towards users, which would value them as people. The consultation therefore endorses the importance of values as being fundamental to the ways that organisations approach working with service users and carers.

6.4 Theme 3: Training

"I have heard staff say we do user involvement and watch them dis-empower clients through poor facilitation skills." (manager)

Training was felt to be important for all the participants associated with user involvement. The consultation produced suggestions as to how such training needed to focus on rights, diversity, communication and capacity building for the mutual benefit of both organisations and users. There was a sense that everybody had something to learn on this journey but equally that service users and carers had the capacity and experience to meaningfully contribute in this area.

Training was seen as having a part to play in empowering service users: "Confidence building is important to empower people to speak up for themselves and articulate their views" (Carers' Group). The latter group also felt that induction to an organisation was important in helping service users/carers to become involved: "Anyone involved in a working organisation should have a detailed knowledge of that organisation ... this can be obtained by induction courses into the organisation".

Training was also seen by some as a way of respecting human rights and diversity. One person, for example, felt that organisations should receive training on awareness of older people's issues such as *ageism* (discrimination on the basis of age). It was also felt that older people could benefit from "training about workers from other cultures so as not to make negative assumptions about their practice or education" (Older People's Advocacy Group).

On the contribution of training to challenging negative stereotyping several groups felt that prejudices towards people with mental health problems, women from the Travelling Community, young people in contact with the criminal justice system and members of the Gay, Lesbian and Bisexual (GLB) community, for example, could be addressed. Some groups felt that the fact that some individuals present with more than one diversity also had to be recognised: "What hasn't worked is the failure to address multiple identities, eg children with a disability and mental health problems: their voices are not heard" (Children's Organisation).

The encouraging thing from the consultations, however, is the willingness expressed by service user/carer groups to actively involve themselves in delivering such training

to staff in organisations seeking to engage with users. One organisation felt that staff may need help to overcome the *fear* of engaging users and that this should happen before any attempts at involvement began. Given the capacity and experience that many such groups state they have, the organisations seeking user involvement should consider availing themselves of this experience as a powerful way of addressing negative attitudes towards user involvement.

6.5 Theme 4: Practicalities

The importance of practical arrangements that should be considered around user involvement is well documented by previous work in this area (see, for example, Levin, 2004; Duffy, 2006). In this consultation, similar points are made on the subject that highlight that involvement is complex and needs to be well thought out. Some groups talked of the need for provision of transport, support with caring responsibilities, payment of expenses and refreshments. One Carers' Group made the following point about the venues for meetings being important:

“Time is critical for carers, despite interest in larger organisations, meetings are usually held at a considerable distance from home – attendance at these meetings would not be feasible.”

The point was also made that people who are involved in consultation need to have documentation and agendas provided in advance of meetings. One group felt that this would be a practical way in which an organisation seeking user involvement could “share power so as we feel equal” (Health Group). Another group made a similar point about being given time to prepare for involvement: “reports in simple language being sent out in advance of meetings gives time for thought on the development of opinions” (Carers' Group).

Another group felt that organisations needed to consider the volume of paperwork that sometimes accompanied requests for user involvement: “Shorter to the point policies are more easily understood, less boring to read and more likely to be used” (Residential Unit for Older People).

The importance of the need to take time to review and evaluate their experience of involvement when consulting service users and carers was also expressed: “significant time is spent following meetings in reviewing how things went, if anything is missed and what actions need to be taken” (Disabled Young People's Group). The importance of relationship building and trust was also seen as important in a practical regard: “Organisations need to build relationships and allow trust to develop” (Youth Justice Group).

The requirement to work at sustaining these relationships is equally made, however: “commitment and sticking power are needed, capacity building is vital”. The notion of consultation fatigue also comes across and one practical suggestion to avoid this was to increase the pool of service users/carers: “... we need to avoid over-consulting the same young people or having rigid expectations of a consultation in a fixed period of time” (Young People's Group).

Concerns were also expressed about practices to avoid in relation to seeking users' perspectives, as the following quote illustrates: "professionals can be uncomfortable with service users and this can create discomfort and then they often try to overcompensate by over-inflating or over reacting to young people's statements" (Young People's Group).

However, another group offers some insight on this point by stressing how important it is for staff to be able to deal with negative attitudes, prejudices and stereotypes, as this was the lived experience of many participants. A minority ethnic group in the consultation also suggested that one way of avoiding discriminatory practice would be to have leaflets/written information provided in different languages. A point on a similar theme is illustrated by an interview respondent who cautions about making assumptions in organising user involvement. The example is provided of an organisation that embarrassed a person with a visual impairment when it provided all documentation for a meeting in font size 18. A more positive response could have been reached if the person had been asked first!

Other points were made to suggest that consultation should be specific and related to a particular aspect of service. For example, "the most important thing, I believe, is that the involvement should be appropriate to the specific service/degree of involvement/impact on a person's life" (Learning Disability Group).

Practical considerations such as timing of meetings, their duration, meeting carer expenses, remuneration and payment are all important as well as the many other points that have been made in this section. Attention to detail on these issues will powerfully convey to service users and carers that organisations are serious about partnership working in terms of user involvement.

6.6 Theme 5: Knowledge of organisations

As the tables below confirm, the majority of groups and individuals consulted had a limited knowledge about the activities of the three organisations sponsoring this work, which for some people did raise questions about the seriousness of their intentions around user involvement. However, both SCIE and RQIA are only quite recently established in Northern Ireland, which may explain why knowledge of NISCC is slightly better.

Table 2: Knowledge of organisations among the 28 groups consulted

| | Yes | No |
|--------------|-----------|-----------|
| SCIE | 10 | 18 |
| RQIA | 12 | 16 |
| NISCC | 14 | 14 |
| Total | 36 | 48 |

Whereas Table 2 describes how often a particular group knew about the organisations, Table 3 describes how often the total individual members in the groups knew about the three organisations.

Table 3: Knowledge of organisations among *individuals* consulted

| | Yes | No |
|-------|-----|-----|
| SCIE | 20 | 124 |
| RQIA | 25 | 119 |
| NISCC | 29 | 115 |

In spite of groups' limited knowledge of the organisations, what consistently emerges in the interviews is a willingness to become involved in the work of all three. A specific question was included in the interview about the contributions that users could make to the work of the three commissioning organisations when the work of each had been carefully explained. A number of interesting suggestions were put forward in relation to the specific work of each of the sponsoring organisations.

A number of such suggestions are already embedded in the organisations' work practices on user involvement. In addition, however, other suggestions were made, for example, the organisations communicating with the public generally about their function, the importance of user-led training for new staff, the need to monitor the practicalities associated with user involvement, which have all been incorporated into the subtext of the main recommendations in this report.

And finally, although many of the groups we consulted saw the three sponsoring organisations as being remote from their lives, they still felt that they had something meaningful to offer, which of itself has to be encouraging. Perhaps this perceived contribution is best summarised by the following thinking from a senior manager in terms of its value:

"Users of services are in the best position to highlight what is good and poor about the services they receive ... they can also provide a very unique insight into how services can be redesigned or improved."

6.7 Theme 6: Support for a user group network

The project team and the commissioning group agreed to the inclusion of a specific question to survey groups about the idea of a *regional network* for service user groups in Northern Ireland. This was felt to be one way of finding out information that might inform a future strategy around user involvement in Northern Ireland (DHSSPSNI, 2007a). Table 4 shows respondents' thoughts on how useful a Northern Ireland network would be in terms of advancing issues around user involvement.

Table 4

| Question 14 | Very useful | Of some use | No use at all |
|---------------------|-------------|-------------|---------------|
| Number of responses | 75 | 66 | 6 (1 group) |

These results appear to confirm that the idea of a service user network was favourably received. Of the people who felt that it would be 'Very useful', the following are some of their ideas on its role and function:

- a forum for service users to network and share information and good practice
- a useful way for geographically isolated groups to make connections and “feel involved in the bigger picture” (Health Group)
- help to pass on knowledge and enable different carers to get involved with statutory agencies, as carers could be represented by different people
- promote a more consistent approach to user involvement
- provide a focal point for engaging with large health and social care organisations
- benchmark services in different organisations and devise common standards for service user involvement
- useful for sharing ideas and support for people promoting user engagement.

A considerable number of responses, however, also indicate that such a network would be of ‘Some use’ and cite the following as reasons for being more lukewarm in their support:

- some groups may not like to share information with others
- worries that this would become another large unwieldy *talking shop* too far removed from the reality of people’s lives to have an impact
- concerns about how it would work in practice, who would lead it and how people would be selected/elected
- some larger, more powerful groups might dominate the agenda and thereby exclude more marginalised/remote groups
- concerns also about how such a network would be resourced
- some members would have to be offered appropriate training to help improve their capacity for being involved in something like this
- another group mentioned that this had to be a user-led network and with a true user ethos, not organised or led by others only representing the views of service users.

One group in the consultation felt strongly that a network would not make a positive difference to advancing user involvement strategically. This group had previously pulled out of a similar network for specifically interested groups. Its members felt that a network could not speak strongly enough on their issues and that these would be watered down. They felt instead that government agencies needed to make the time and effort to go directly to groups instead of trying to access people through such a network.

6.8 Theme 7: Feedback and outcomes

“Service users are often asked for opinions but rarely does anything change to the provision of care.” (Young Carers’ Support Group)

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

The issue of *consultation fatigue* is referred to in the literature section of this report. Many organisations consulted in this study felt that being given *feedback* and information about the *outcomes* of their involvement were both essential in

the process of being valued and also in encouraging willingness around future user engagement with organisations. When feedback is not given, comments such as the opening quotes above will inevitably become more commonplace.

The issue about user involvement being associated with tangible outcomes is felt to be very important, as the following quote affirms: “We need to see that what we are being consulted about is making a difference” (Older People’s Group). Another group made a similar comment and suggested that user involvement should not be “viewed as a one-off event” (Older People’s Advocacy Group) and the importance of “users wanting acknowledgement” (Children’s Group) was also seen as important.

This notion of feedback is also important in terms of perceptions of government organisations’ attempts at user involvement, as the following suggests: “we don’t have feedback on the actions taken or the results or how distance has been reduced...” (Young People’s Group). Other groups felt that getting feedback from organisations was important to “demonstrate impact – how services changed because of service user/carer involvement” (Advocacy Group for Learning Disability). Another group expressed frustration over consultations where there was no feedback and where participants were left feeling “used” as a result. This group felt that feedback was very much seen as “good manners” which links to the earlier point made about *humanity* as a value being important in this work (User-led Group).

On a similar theme to this, another example of this feeling of *being used* was voiced by a Carers’ Group who felt demoralised when their opinions were taken by others and no one ever returned to thank them, acknowledge them or to say what a difference their views had made. A constructive suggestion is made, however, by the following group as a practical way in which these problems could be avoided: “In a waiting room possibly at the door on the way out, someone asking questions on how users ‘carers’ experience was today, any suggestions for improvement etc” (Residential Unit for Older People).

What this section clearly shows is that service user/carer groups must be valued in terms of their involvement and this can be shown in concrete terms by telling the groups/individuals how their involvement has/or has not changed things. Working in this way will go a long way to ensuring that such groups do not express the negative feelings that the absence of such feedback inevitably causes.

The interview also included a question aimed at determining users’ level of satisfaction with existing user involvement/consultation approaches from HSSTs. The responses are summarised as follows in Table 5.

Table 5

| Question 12 | Very good | Satisfactory | Not very good |
|---------------------|-----------|--------------|---------------|
| Number of responses | 3 | 13 | 127 |

These are important findings given what they tell us about the enormity of the challenges facing larger organisations seeking to pursue the involvement of users. What is even more concerning, however, is the number of people who had such

poor experiences of involvement. Some groups answering this question expressed a preference for having an option that was stronger than 'Not very good'! When some of the reasons behind such negative experiences are more closely examined, there could be better awareness of what needs to be avoided in terms of trying to make user involvement work:

- Some respondents noted that where you lived in terms of trust area influenced experiences of user involvement in Northern Ireland.
- One group felt that it was “trundled out” when a model of user involvement needed to be shown and at such times this caused suspicion and at worst fear about raising expectations that may go unmet.
- The impetus for involvement came from groups and not statutory providers.
- User involvement needed to be more user-driven and policy-based – stronger relationships needed to be forged with the voluntary sector.
- Users were only being consulted at *defined stages* instead of being involved throughout the *process* of service development.
- Organisations needed to work at hearing the views of small, *complex populations*, such as people with a learning disability, who found it difficult to have their views heard about health and social services unless there was a *specific consultation* about learning disability services.
- There was an over-reliance on the complaints system to gather views in a negative way or other unsophisticated consultation exercises did not work.
- One group of women felt that the government had no interest in their opinions based on previous negative experiences of oppression and discriminatory attitudes by *professional* staff. This group felt that they could make a real contribution to planning services but staff had not given them the opportunity.

It has to be said, however, that many groups also reported positive experiences with individual staff members, but this did not apply collectively to the organisation, which is significant in terms of user involvement needing to be seen as a *way of working* and *thinking*.

6.9 Theme 8: Resources

The issue of additional resources needed to support user involvement initiatives also features with some consistency in the findings. In addition to the need for practical resources such as transport costs, payment, caring expenses, refreshments and so on, several groups suggested the need to have a *dedicated staff member* in each organisation to act as a single point of contact for supporting service users and carers. It was suggested that this nominated person should have a budget set aside for user involvement consultation.

The community outreach suggestion mentioned already under the communication theme would also inevitably incur additional resources but was felt to be important: “try to get into communities and be innovative ... try to de-stigmatise through approaches such as one-stop shops ... outreach to vulnerable communities through networks and links is very important” (Children’s Advocacy Group).

The notion of secondment was also felt to be a practical way in which host organisations could get closer to understanding user perspectives: “larger organisations must invest in participation work; speak to experts, get guidance and share good practice ... this can happen through secondments and releasing people” (Young People’s Support Group). The issue of investing resources to enable users to empower themselves was also made. However, there was also a sense of realism that any person designated in organisations to coordinate and facilitate work in this area “needs to have the visible support of a senior member of the trust board in order to drive the changes often required” (Hospital User Forum).

6.10 User groups consulted: important messages

The following are principles and points of good practice that the project team identified from the consultations with the user groups and felt worthy of highlighting. The content of this section is also linked in with the themes and related recommendations of the report, as is indicated below.

- User involvement can also be facilitated by situations where users know they have an avenue in which to have their voices heard. People do not always have to be present in person – the fact they know that such an avenue exists is often enough. (*Themes: Communication, Values*)
- The life experience of being a user of services affords such individuals the right to involvement. (*Theme: Values*)
- Users should be consulted *from the start* in relation to new initiatives that organisations are planning where user participation is desirable. A *circle* approach starting with the user rather than from the top down may be one way for organisations to do this. An example of this in practice is where, for example, documents are developed firstly along with service users/carers and then consultation is asked for *after* this initial process is complete. (*Themes: Communication, Practicalities*)
- Past *negative experiences* of user involvement may make some people cautious towards future involvement – this is something that could be addressed through induction training for service users and carers prior to involvement commencing. (*Theme: Training*)
- Having a ‘how can we make it happen?’ culture which is open to change and to new ways of doing things, rather than a risk-averse, minimalist approach, will support user involvement initiatives in an organisation. (*Themes: Values, Practicalities*)
- The idea of users conducting a *walk through* of organisations may be a useful way for organisations to audit aspects of its accessibility around user issues. (*Theme: Practicalities*)
- Continuing involvement with larger organisations calls for considerable *stamina* on the part of users. People therefore need to feel *supported* in the process of user involvement. Key staff should spend time, following user involvement events, *reviewing* how things went with group members to see if anything was missed and what actions need to be taken in terms of future involvement. (*Themes: Feedback and outcomes, Values*)
- *Listening groups* may represent an effective way of ensuring that a cross-section of users are consulted about a particular issue. Here, people are carefully selected

to ensure even representation in terms of gender, geography etc. Information for such events is given one week in advance, hospitality is provided, a round table discussion takes place in which everybody participates and everything discussed is written up afterwards and shared with the participants. (*Themes: Communication, Practicalities, Values*)

- The user perspective should be the *core value* at the heart of everything an organisation does. The first meeting for any new staff member should be with the staff member responsible for participation. User involvement should be present at *every level* of an organisation's activities. (*Themes: Values, Training*)
- Effective user involvement can also occur where this is *facilitated* by a staff member. It is important that people feel respected, valued and important in this process. A *tick-box* approach to user involvement has to be avoided. *Relationship building* needs to be at the centre of the process where people feel respected and *treated with importance*. This will contribute to *trust building*. (*Themes: Communication, Values, Training*)
- Information has to be *understandable* and *accessible* to everybody given the problems that many people experience with literacy. This is important when working with people *on the fringes*.
- Organisations should commit to the principles of *advocacy* when working with groups such as children in the area of participation. (*Theme: Values*)
- *Pre-consultations* and *step-wise* approaches are suggested as ways of checking understanding among users that cannot be assumed. (*Themes: Practicalities, Communication*)
- *Feedback* following any consultations is important and should be done in a way that avoids the use of jargon. (*Themes: Communication, Feedback and outcomes*)
- It is important to be asked for users' opinions in a way that attempts to *understand their needs*. Again the experience of being involved in *focus groups* is recorded as being positive in relation to this. (*Themes: Communication, Values*)
- Engagement with some particular groups, who have little experience of participation, may be best achieved through an *outreach approach* by organisations which might in turn lead to such members developing confidence and capacity to become involved in the work such organisations in the future. (*Theme: Communication*)

7 Conclusion

The consultation presents the three commissioning organisations with quite detailed information about many aspects of user involvement that should help inform their attempts at progressing initiatives in their respective roles and also in a way that sees all three bodies working more closely together. The evidence from this relatively small-scale consultation would suggest that many users consulted had negative experiences of involvement with large-scale health and social care providers in Northern Ireland. On a more positive note, however, each of the themes emerging from the consultation includes suggestions for ways in which such negative experiences could be avoided. In addition, there are many examples of positive practice.

This work does not attempt to provide all of the answers in what is a complex area. What it does do, however, is help point the three organisations in directions that should be helpful in enabling them to achieve user participation in a way that is meaningful and worthwhile for all involved.

Appendix 1: User involvement definitions

Service user: Armstrong (2005) locates the term 'service user' as having been around for more than 15 years and offers the following definition: 'Anyone who needs long term care or support or who uses services intensively for a short period of time' (2005, p 4). Armstrong also encourages us to think about some of the more negative meanings associated with *service user* based on reactions from people to whom the term is meant to refer. The following statement speaks for itself: 'I'm no user, I'm not a sponger!' (Armstrong, 2005, p 5). Levin (2004) agrees that the term 'service user' does not enjoy any consistency in terms of meaning or to whom it applies. She states that many people are uncomfortable with it and prefer terms like *client* or *consumer*, because they believe that *service user* is negative in the way it defines people by the services they use and as such is disempowering.

This more inclusive thinking on service users is also popular in government thinking. Swift (2002), for example, writing for the Department of Health, talks about service users not only in terms of current eligibility to access social work services but also as potential users of such services at some point in the future. This more flexible approach is also currently evident in Northern Ireland where reference to service users is now described as *personal and public involvement* (PPI) by the DHSSPSNI in its draft guidance on the involvement of service users in health and social care (2007b). The *personal* is used to refer to an individual's experience of services whereas the *public* refers to the fact that every member of the public is a potential user of such services.

User: this term is frequently referred to as meaning *service user* but is nonetheless equally problematic. Its connotation to substance abuse (Chamberlain, 1993) and colloquial association with in some way taking advantage of the system, detract from its popularity. Having said this, the word *user* does now appear embedded in the language associated with service user involvement. For example, Shaping Our Lives Network uses the term *user-controlled* to explain the way in which some user organisations are organised and managed.

Carer: the term *carer* is globally defined as involving a diverse and complex nature of caring activity impacting on various people at different ages. Levin (2004) describes a carer as being someone who looks after a friend, partner or family member who is ill, frail or has a disability and that such work is unpaid and includes a wide spectrum of activity. A similar definition is offered by DHSSPSNI (2002) that describes carers as 'people who, without payment, provide help and support to a family member or friends who may not be able to manage at home without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people under 18 who care for another family member' (2002, p 6).

Appendix 2: Groups participating in the consultation

Disability Action

Mencap

Praxis Care Group

Age Concern

Voice of Young People in Care (VOYPIC)

Include Youth

Northern Ireland Council for Ethnic Minorities

Carers Northern Ireland

The Rainbow Project Children in Northern Ireland

Carers and Users Support Enterprise (CAUSE)

Gingerbread Northern Ireland

The Cedar Foundation User Forum

Barnardo's Young Carers

The Firs Private Nursing Home

Corkhill Lodge Private Nursing Home

The Relatives Group

Eastern Health and Social Services Board

The Mater Hospital Community User Forum

Marie Curie User Group

Prosthetics Users Forum, Green Park Health Care Trust

Western Health and Social Services Board

Mind Yourself

Diabetes Support Group

Foyle Carers

Northern Health and Social Services Board

Triangle Housing Association

Ladies Mental Health Support Group and Reability, Rathenraw Estate

Newtownabbey Senior Citizens Forum

Southern Health and Social Services Board

Women and Family Health Initiative

Sixth Sense Young People's Project (Wraparound)

Carers Forum SHSSB

Appendix 3: Interview schedule

SCIE user involvement consultation

Information for research participants

Thank you very much for agreeing to be interviewed for this project. It is important for me to explain why we are carrying out this study. In Northern Ireland there are health and social care groups and organisations that have an interest in people's health and well-being. These groups and organisations plan, provide, check on and/or buy services. In recent years many people are realising that to do this better, those groups and individuals who use services or care for those who do, should be involved in the organisation and delivery of these services. This process is often called 'user and carer involvement'; this project is about this issue.

The aim of the project is to advise a number of organisations about how user and carer involvement is organised, and could be improved in Northern Ireland. These organisations are the Northern Ireland Social Care Council (NISCC), the Regulation and Quality Improvement Authority (RQIA) and the Social Care Institute for Excellence (SCIE). I can provide you with more information about these organisations if you wish.

This interview is being used to find out about the nature of service user and carer involvement in your organisation. It will involve in total 13 questions and should take about 30 minutes. The person undertaking the interview will also be taking notes of your responses during the interview. Please do not hesitate to stop the person if you are not sure about what the questions mean, or if you need more information. If you do not wish to answer specific questions please say so. You can also stop the interview at any stage if you so wish.

It is important to tell you that the information received from your interview will be treated in the strictest of confidence which means that neither your name nor the name of your organisation will be linked to your interview or when the report of the findings of the project is published. Do you have any questions at this point?

Interview questions

1. Do you know what the Regulation and Quality Improvement Authority (RQIA) is?
Yes No If yes, can you explain in your own words?

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2. Do you know what the Social Care Institute for Excellence (SCIE) is?

Yes No If yes, can you explain in your own words?

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3. Do you know what the Northern Ireland Social Care Council (NISCC) is?

Yes No If yes, can you explain in your own words?

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4. Why is it important for health and social care organisations to involve service users and carers? *(Prompts: those receiving services have an important say in how such services are organised, accessibility of the organisation, user issues kept to the fore)*

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5. There are different ways of involving service users/carers in this way. Could you provide me with practical examples of what works or has not worked for your organisation/group? *(Prompts: being asked for opinion/say on important documents, getting reports well in advance in language easily understood, attending meetings at times that suit, having a say at meetings/agenda setting for example)*

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6. How might larger health and social care organisations (like trusts and government organisations) achieve service user and carer involvement? *(Prompts: having policies on user involvement, having it mainstreamed throughout the organisation as a way of thinking, thinking about it naturally)*

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7. Can you give practical examples of what you think works or does not work in terms of service user/carers involvement in these larger organisations? *(Prompts: accessibility, understandable material in plain language, induction etc)*

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8. RQIA (one of these larger organisations) is the organisation with responsibility for making sure that the public receives a quality health and social care service – what part do you think service users/carers can play in this organisation? *(Prompts: on management groups, as lay inspectors, involved in writing standards)*

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9. NISCC (another one of these larger organisations) is the organisation with responsibility for making sure that the people who provide social care services do so to a high standard – what contribution can service users/carers have in this organisation? *(Prompts: part of the Council itself, a member of a user/carer group linked to the Council, taking part in Council consultations, involved in focus groups, perhaps some other way – please state – of influencing the way the Council works. Is there any part of the Council’s work that you are particularly interested in?)*

.....

10. SCIE, also a large organisation, aims is to improve the experience of people who use social care by developing and promoting knowledge about good practice – how can service users and carers influence the way this organisation works? *(Prompts: involvement in management of the organisation, ensuring wide range of people are consulted about social care issues, ensuring publications are accessible)*

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11. In terms of involving the opinion of service users and carers, do you think government organisations like health and social services trusts are:

- Very good at involving users and carers
- Satisfactory at involving users and carers
- Not very good at involving users and carers

12. What do service users/carers need to be effectively involved in organisations like RQIA and NISCC? *(Prompts: skills, knowledge, resources, induction)*

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13. What skills are necessary for staff in health and social care organisations to have when working with service users/carers? (*Prompts: reliable, partnership working, respectful, effective at communicating*)

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14. How useful do you think it would be to have a Northern Ireland network for service user groups that would bring together users from different organisations and from different parts of Northern Ireland?

Very useful Of some use No use at all

Once again, many thanks for agreeing to take time to complete this interview, it is very much appreciated. When the final report is published, you or your organisation will have an opportunity to attend the launch and receive copies of the report.

Appendix 4: Policy and legislative themes on user involvement: Northern Ireland and United Kingdom

The following table outlines the important events that have helped shape user involvement over the past 20 years within Northern Ireland and the UK.

| UK context | Northern Ireland context |
|--|---|
| <p>2006 <i>Our health, our care, our say</i>, a White Paper stipulating that people should be given a 'stronger voice' and become 'the major drivers of service development' (DH, 2006a, p 5)</p> | <p>2007 <i>Health and Social Services (Reform) (NI) Draft Order</i>. Articles 13 and 14 proposed a statutory duty of personal and public involvement (PPI) and consultation on health and personal social services (DHSSPSNI, 2007b)</p> |
| <p>2006 <i>Reward and recognition</i>, a guide for service providers, service users and carers (DHSSPSNI, 2006a)</p> | <p>2007 <i>The priorities for action 2007–2008</i> emphasised the need for greater user and carer involvement as advocated in the Quality Standards. These priorities also stated 'service users and carers should be involved in developing, delivering and evaluating services' (DHSSPSNI, 2007c, p 12)</p> |
| <p>2006 National Health Service Act (England) required patient forums to be established in each NHS trust, with a role to monitor and review the range of services provided or arranged by the trust (DH, 2006b)</p> | <p>2006 DHSSPSNI produced <i>The quality standards for health and social care</i> by which the boards and trusts would be inspected. These were hailed as 'a significant step in the process of placing the needs of the service user and carer, and the wider public at the centre of planning, delivery and review of health and social care services' (DHSSPSNI, 2006b, p 1)</p> |
| <p>2003 <i>Building on the best choice</i> highlighted the relationship between choice, service responsiveness and equity (DH, 2003a)</p> | <p>2004 <i>A healthier future 2005–2025</i> had 'involving people' as a key theme and advocated that 'planning and delivery of services be person and community centred' (DHSSPSNI, 2004b, p 37)</p> |
| <p>2003 <i>Department of Health priorities framework 2003–2006</i> highlighted the priority of 'improving the overall experience of patients' and emphasised the need to defer to patient and public as well as professional knowledge (DH, 2003b, p 5)</p> | |
| <p>2002 The establishment of a Commission for Patient and Public Involvement in Health (England)</p> | |

UK context

2001 Section 11 of the Health and Social Care Act placed a duty on all NHS trusts to involve and consult with patients and the public, not only in decisions about treatment but also in the planning and development of health and social care services

2001 Bristol Royal Infirmary Inquiry (www.bristol-inquiry.org.uk/) highlighted the importance of patient and public involvement in creating a more open and accountable health service

2001 *Improving health in Wales* (www.wales.nhs.uk/publications/struc-consul-report-e.pdf) emphasised the role of citizens and communities in developing health policy

2000 *The NHS Plan* began to formalise the requirements of modernisation through the introduction of clinical governance, patient-centred care and services developed 'around the needs and preferences of individual patients, their families and carers' (DH, 2000, p 7)

2000 *Our national health (Scotland) strategy* (Scottish Executive, 2000) recommended that individuals, groups and communities should be involved in establishing priorities and in service planning

1998 Human Rights Act – see opposite

1997 New Labour's ***The NHS: Modern, dependable*** stated that to restore public confidence in the NHS, services needed to be more 'accountable to and shaped by' the views of the public (DH, 1997, p 4)

Northern Ireland context

2003 *Health and Personal Social Services (Regulation and Quality Improvement) NI Order* established the RQIA, and placed a legislative duty of quality on all HSSBs and HSSTs for all the services they provided and commissioned (DHSSPSNI, 2003)

2002 *Investing in health, working with communities* (DHSSPSNI). The involvement of patients and communities is seen as crucial to the future development and success of health and social care programmes throughout Northern Ireland

2001 *Best practice, best care*, a consultation paper, proposed a new framework to improve quality through clinical and social care governance. It also paved the way for the development of a statutory duty of quality and an independent authority for inspecting, regulating and improving quality in health and social care services (DHSSPSNI, 2001)

1998 Human Rights Act introduced in Northern Ireland in October 2002 places legal requirements on public service providers to comply with the European Convention on Human Rights (ECHR). Article 6 refers to rights to a fair trial or the right to be heard, and applies to user involvement

1998 Northern Ireland Act introduces through Section 75 the need for all public service providers to promote equality of opportunity in their activities

UK context

1992 *Local voices* stipulated that services should be more responsive to patient needs and that communities should help to develop services, and evaluate them (DH, 1992)

1991 *The patients and citizens charters* established a number of patient rights around consultation and minimum standards (DH, 1991)

1990 The NHS and Community Care Act was the first piece of legislation that formally required local authorities to consult with users and carers in relation to service planning (Farrell, 2004)

1989 Children Act introduced the concept of working in partnership with children and families

1989 United Nations Convention on the Rights of the Child (UNCRC) emphasised children's rights to participation in services

Northern Ireland context

1997 *The regional strategy for health and social well-being 1997–2002* developed People First principles further by stating that 'there should be meaningful consumer involvement at all levels of service planning, commissioning and provision and support for the development of user led groups and services' (DHSS, 1997, p 10)

1995 Children (NI) Order introduces requirements for public authorities to work in partnership with children and families

1991 The patients and citizens charters established a number of patient rights around consultation and minimum standards (DH, 1991)

1991 *People first* identified one of the underlying principles of community care to be that 'services should respond flexibly to the needs of individuals and the relatives and friends who care for them' (DHSS, 1991, p 5)

1989 UNCRC – see opposite

References

- Armstrong, T. (2005) Dissertation submission for MSc in Advanced Social Work, Queen's University Belfast and University of Ulster.
- Bamford, D. (2005) *The review of mental health and learning disability (Northern Ireland): A strategic framework for adult mental health services*, Belfast: DHSSPSNI.
- Barker, I., Newbiggin, K. and Peck, E. (1997) 'Characteristics of sustained advocacy projects', *Community Care Planning and Review*, vol 5, pp 132–8.
- Barnes, M. and Shardlow, P. (1997) 'From passive recipient to active citizen: participation in mental health user groups', *Journal of Mental Health*, vol 6, no 3, pp 289–300.
- Bowl, R. (1996) 'Involving service users in mental health services: social services departments and the National Health Service and Community Care Act 1990', *Journal of Mental Health*, vol 5, no 3, pp 287–303.
- Campbell, J. and Wilson, D. (2004) *Unmet need: A study of mental health legal advice and information services in Northern Ireland*, Belfast: Law Centre (NI) Nuffield.
- Chamberlain, A (1993) 'Working towards user-led services through a mental health forum', *Community Health Action*, vol 8, Spring, pp 6–8.
- Chambers, R., Drinkwater, L. and Boath, E. (2003) *Involving patients and the public: How to do it better*, Abingdon: Radcliffe Medical Press.
- Conn, L. (2006) *A literature review to inform the inspection of social care services for carers of older people in Northern Ireland*, Belfast: DHSSPSNI.
- DH (Department of Health) (1991) *The patients charter*, London: DH.
- DH (1992) *Local voices*, London: DH.
- DH (1997) *The NHS: Modern, dependable*, London: DH.
- DH (2000) *The NHS Plan: A plan for investment, a plan for reform*, London: DH.
- DH (2003a) *Building on the best choice: Responsiveness and equity in the NHS*, London: DH.
- DH (2003b) *Department of Health priorities framework 2003–2006*, London: DH.
- DH (2006a) *Our health, our care, our say*, London: The Stationery Office.
- DH (2006b) *National Health Service Act (England)*, London: The Stationery Office.
- DHSS (Department of Health and Social Services) (1991) *People first: Community care in NI for the 1990s*, Belfast: DHSS.

- DHSS (1997) *The regional strategy for health and social well-being 1997–2002*, as cited in SSI (1997) *Consumer involvement changing attitudes*, Belfast: DHSS.
- DHSSPSNI (Department of Health, Social Services and Public Safety Northern Ireland) (2001) *Best practice, best care*, Belfast: DHSSPSNI.
- DHSSPSNI (2002) *Valuing carers: A strategy for carers in Northern Ireland*, Belfast: DHSSPSNI.
- DHSSPSNI (2003) *Health and Personal Social Services (Regulation and Quality Improvement) NI Order 2003*, London: The Stationery Office.
- DHSSPSNI (2004a) *Equality and inequalities in health and social care: A statistical overview*, Belfast.
- DHSSPSNI (2004b) *A healthier future 2005–2025*, Belfast: DHSSPSNI.
- DHSSPSNI (2006a) *Reward and recognition: The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers*, Belfast: DHSSPSNI.
- DHSSPSNI (2006b) *The quality standards for health and social care*, Belfast: DHSSPSNI.
- DHSSPSNI (2007a) *Draft framework for stakeholder involvement in health and social care*, November, Belfast: DHSSPSNI.
- DHSSPSNI (2007b) *Health and Social Services (Reform) (NI) Draft Order*, Belfast: DHSSPSNI.
- DHSSPSNI (2007c) *The priorities for action 2007–2008*, Belfast: DHSSPSNI.
- Duffy, J. (2006) *Participating and learning: Citizen involvement in social work education in a Northern Ireland context* (www.swap.ac.uk, www.scie.org.uk, www.niscc.info).
- Farrell, C. (2004) *Patient and public involvement in health: The evidence for policy implementation*, London: DH.
- Fay, M.T., Morrissey, M. and Smyth, M. (1999) *Northern Ireland's troubles: The human costs*, London: Pluto.
- Hasler, F. (2003) *Users at the heart: User participation in the governance and operations of social care regulatory bodies*, SCIE Report No 5, November, London: SCIE.
- Hirschman, A. (1970) *Exit, voice or loyalty*, Cambridge, MA: Harvard University Press.
- Levin, E. (2004) *Involving service users and carers in social work education*, London: Social Care Institute for Excellence.

- Lorenz, W. (1994) *Social work in a changing Europe*, London: Routledge.
- McKeever, B. (2000a) *Bridging the gap*, Derry: Guildhall Press.
- McKeever, B. (2000b) *Listening to parents: Parents as professionals*, Derry: Guildhall Press.
- McKeever, B. (2001a) *Time to act*, Derry: Guildhall Press.
- McKeever, B. (2001b) *In the telling*, Derry: Guildhall Press.
- McKeever, B. (2002) *Beyond words*, Derry: Guildhall Press.
- McKeever, B. (2006) *Making the impossible possible*, Derry: Guildhall Press.
- Manning, D. (2004) *Mapping examples of user involvement in Northern Ireland*, Macmillan Cancer Relief.
- Meyer, J and Timms, N. (1970) *The client speaks*, London: Routledge & Kegan Paul.
- NHSSB (Northern Health and Social Services Board) (2001) *Policy for public involvement*.
- Olsen, R., Parker, G. and Drewett, A. (1997) 'Carers and the missing link: changing professional attitudes', *Health and Social Care in the Community*, vol 5, pp 116–23.
- Peck, E., Gulliver, P. and Towel, D. (2002) 'Information, consultation or control: user involvement in mental health services in England at the turn of the century', *Journal of Mental Health*, vol 11, pp 441–51.
- Pilgrim, D. and Waldron, L. (1998) 'User involvement in mental health service development: how far can it go?', *Journal of Mental Health*, vol 11, no 1, pp 95–104.
- Scottish Executive (2000) *Our national health: A plan for action, a plan for change* (www.scotland.gov.uk/library3/health/onhbn-oo.asp).
- SHSSB (Southern Health and Social Services Board) (2007) *Together we make a difference*.
- Swift, P. (2002) *Service users' views of social workers: A review of the literature undertaken on behalf of the Department of Health*, London: Institute for Applied Health and Social Policy, King's College London.
- WHO (World Health Organization) (1978) *Primary health care*, Geneva: WHO.
- Wilson, G. and Daly, M. (2007) 'Shaping the future of mental health policy and legislation in Northern Ireland: the impact of service user and professional social work discourses', *British Journal of Social Work*, vol 37, no 3, pp 423–39.

Looking out from the middle: User involvement in health and social care in Northern Ireland

This report explores user involvement in health and social care services for both adults and children in Northern Ireland. The report looks at how NISCC, RQIA and SCIE can strengthen user involvement by working more closely together in this area.

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