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BACKGROUND

On 1 January 2000, Section 75 of the Northern Ireland Act 1998 came into effect requiring public authorities, in carrying out their duties relating to Northern Ireland, to have due regard to the need to promote equality of opportunity between certain individuals and groups: The act established 9 categories i.e.

Between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and woman generally; between persons with a disability and persons without; and between persons with dependants and those without.

Section 75 also requires without prejudice to the above that public authorities have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group. Everyone in society will belong to at least one of these categories. Most people will fit into a number of categories. The legislation therefore has very wide implications.

Under Schedule 9 of the Act, Public authorities are required to produce Equality Schemes conforming to Guidelines set out by the Equality Commission with the approval of the Secretary of State, to underline how they are going to undertake these duties, and to specify a timetable for implementing the proposed equality measures.

In taking this requirement forward the Health and Personal Social Services in the Western area have taken the opportunity to work closely together and have formed an Equality and Human Rights Forum. Membership of the Forum includes representation from

- The Western Health and Social Services Board
- Altnagelvin Hospital Trust
- Foyle Health and Social Services Trust (including Westcare Business Services)
- Sperrin Lakeland Health and Social Services Trust
- Western Health and Social Services Council

Alongside this the Health and Personal Social Services family expressed the view that Good Practice Reviews would support the program of Equality Impact Assessments. Issues, which will be subject to Good Practice Reviews, include:

- User Involvement
- Access to Information
- Complaints Procedures
- Staff Attitudes to Diversity

The Western Area has been assigned responsibility to lead on developing a Good Practice Review in relation to User Involvement. The purpose of this Good Practice Review is to develop a set of guidelines, which will identify best practice in the involvement of Users in the planning, and delivery of health

and personal social services. These Guidelines will be widely available to the Health and Personal Social Services in general.

AIM

To determine the views and experiences of Health and Personal Social Services Providers and Users. From the information gained, develop a set of guidelines, which will outline how users should be involved in both the planning and delivery of services. The guidelines critically should highlight how user involvement is mainstreamed with Health and Personal Social Services Organisations.

OBJECTIVES

To analyse the responses of questionnaires from Health and Personal Social Services providers to aid in the formulation of user involvement guidelines for future service development.

To develop primary research which targets Health and Personal Social Services Providers, Community and Voluntary Groups and individual users thus formulating practical guidelines, which give direction to mainstreaming User Involvement in the Health and Personal Social Services.

To facilitate Focus Group discussions with the Community and Voluntary sectors and Users, to inform the development of User Involvement Guidelines.

LITERATURE OVERVIEW/USER INVOLVEMENT

It is increasingly being acknowledged that public health service providers need to consult and involve their users when planning and delivering the health services they provide. Although there is continuing effort to engage users in order to improve service quality, it is still recognised that more needs to be done in order to ensure sustainability of user involvement.

As part of this research an intensive literature overview was carried out which examined case studies, journals and articles that identified areas, and examples of good practice in User Involvement.

On reviewing the literature there are a number of categories under Section 75 of the Northern Ireland Act which are largely under represented as there is a dearth of research available for specific groups eg religious beliefs and sexual orientation.

METHODOLOGY

Participants and Sampling Strategy: There were two categories of participants. These were

1. All Health and Personal Social Service Providers in Northern Ireland
2. All Community and Voluntary Groups, and interested individuals held on the Western Area Boards Equality and Human Rights mailing list.

In total 35 Health and Social Service providers in the Northern Ireland were contacted by mail and of these 28 responded.

48 responded from the Community and Voluntary sector.

RESEARCH TOOLS

Separate questionnaires were designed for Health and Personal Social Services providers (see appendix 1) and the community and voluntary sectors (see appendix 2).

Focus Group discussions were also carried out with 12 Community and Voluntary Groups. Themes to be discussed were based on information gained from the literature overview on User Involvement (see appendix 3).

Follow up telephone interviews were made to 15 Health and Personal Social Services providers.

PROCEDURE

Health and Personal Social Service Providers (HPSS)

All Health and Social Services providers received a letter by mail (see appendix 4), which outlined the study and sought a response on their willingness to participate. A questionnaire was then delivered to all the Health and Social Services providers by post. This was followed by telephone interviews seeking further information on projects identified by the Health and Personal Social Services providers in the questionnaires.

Community and Voluntary Groups and Individuals

A letter outlining the study and asking for co-operation in taking this project forward was sent to all groups and individuals on the WHSSB's Equality and Human Rights Departments mailing list.

An initial mailshot of 25 questionnaires was sent out to all parties who had expressed an interest in taking part followed by the delivery of questionnaires by post to all remaining parties on the mailing list (see Appendix 5). This was then followed by 12 Focus Group discussions in a number of areas throughout the WHSSB area. A number of semi structured questions were developed for the Focus Group discussions but deviation from the questions was permitted.

Qualitative responses to the questionnaires were transcribed and emerging themes recorded, while quantitative data was entered onto SPSS ver.10™ (Statistically Package for Social Sciences) and analysed (see Appendix 6 and Appendix 7).

RESULTS

The results are broken down into four sections.

1. Health and Personal Social Services Providers Questionnaire.
2. Community and Voluntary Groups and Individual Questionnaire.
3. Health and Personal Social Service Providers Telephone Interviews.
4. Community and Voluntary Group Focus Group discussions and semi-structured one to one interviews.

The Source information from the Literature Overview, Focus Group discussions, questionnaires and individual interviews can be referred within the “Have Your Say”.

LITERATURE OVERVIEW/USER INVOLVEMENT

On reviewing the literature there are a number of categories under Section 75 of the Northern Ireland Act which are largely under represented as there is a dearth of research available for specific groups. However, with the exception of people of different religious beliefs and people of different political opinion who can be encompassed within the other groupings, all other categories have focused in the present research and the views of people representing these specific groups have been documented in this report.

Introduction

We may all want to be involved in deciding about the health services we receive, but we all don't want to be involved in the same way. The particular requirements and what is deemed to work and what is felt does not work for different service users found in the overview of literature are listed below.

Mental Disability

It has been found that users of mental health services do not identify with their needs in the same way as health professionals and that they have different priorities (Hogman, G. 1993). Nurses put drug treatment and being seen at ward rounds or case conferences as high priority while patients themselves see this as low importance.

Another important finding is that users of mental health services have low expectations, because they are so used to having services done to them and not with them. This then often leads to uncertainty for the user when asked what would be needed to improve services for them. This is said to be because users are not informed enough and need to be equipped with all the necessary information about the service. This may include an understanding of how the planning cycle works, job descriptions of various professionals, people's rights, the level of available resources etc. The mental health services that have been reviewed have dealt with this problem in a number of ways.

Some authorities in England pay users as consultants, and provide finances and facilitators for them to set up independent groups to represent users in planning. (Hogman, G.1993).

Other groups have developed policies in order that user representatives can participate fully in the planning process. These include, a policy on jargon, "use language that all users will understand". A policy that all travelling and administration expenses are met etc. (Hogman, G. 1993).

Cornwall rural community council, funded by the Health Authority and Social Services has employed a dedicated user involvement worker whose role is to co-ordinate six district users forums across Cornwall. (Strategic Health Authority area: The Peninsula 2000). These are open meetings for people with mental health issues to look at mental health services. Provides independent visiting of in-patient units to

talk to user forums and to talk about their experiences. Users feedback to user visitors about quality of service. Independent care plans and self-assessment questionnaires are also used.

In response to users in Cornwall reporting that they felt that they were often admitted to psychiatric inpatients units because there was no alternative, the user co-ordinate asked what the alternatives would be.

Suggestions made were,

The provision of a safe house with workers employed by the rural community council. Host families were to be recruited and trained.

A budget to made available to each community mental health teams to bug individual sanctuary packages in a chosen place detailed in the care plan and used when users decide that it is needed.

Services that have been developed with user input also in Cornwall include,

- A helpline funded by the Health Authority, offering support and listening.
- A service that provides face to face contact to people on enhanced care plans at night if they feel there is something they cannot deal with until morning.
- Specialist advice is also offered at night by trained nursing staff from 8.30pm to 8.30 am for users and carers.

Cornwall community rural council felt that by employing a user co-ordinator that it allows for continuity, it provides support for groups when needed and it also co-ordinates training and recruitment of volunteers. (Strategic Health authority area: The Peninsula 2000).

User groups that have been set up by district health authorities and financially supported by them appear to be most successful when they have a development officer/facilitator working with them.

Mental Disability/Deafness

The NHS Health Advisory Service's 1998 Executive Summary of Mental Health Services for Deaf people found that in taking into account users' views and those of professionals in Health and Personal Social Services departments, few staff in the statutory and non-statutory organisations have adequate knowledge of the mental health needs of deaf people, the services currently available, or how to gain access to them.

Deaf people of all ages have limited access to local health services because of poor communication with hearing professionals.

Few districts have effective, planned and co-ordinated mental health services for deaf people. Some of the recommendations made to alleviate these problems were

Whether the patient has difficulty hearing or speaking, wherever possible an approved social worker with appropriate communication

skills should carry out assessments or assist the approved social worker assigned to the case.

The patient's culture background should be considered.

Doctors should receive guidance from local authorities on the use of interpreter services. There should be suitable arrangements in place for availing of these services.

MIND

MIND, another service for people with a mental health disability feel that user involvement has taken off in the last decade but there is still a long way to go.

MIND believes that users should have the opportunity to be involved in decisions regarding aspects of mental health services, from their individual care and treatment to local and national policy. It was suggested that to further advance user involvement all service providers should

- Offer users the chance to be involved in deciding who their key worker or psychiatrist is.
- Users should be involved in drawing up their care plan.
- Users should be offered support to withdraw from medication if they wish.
- Staff should be trained on the Mental Health Act code of Practice.

Full user involvement to them means;

Equal citizenship, dignity and respect in mental health services. Full information in treatment and care. Independent advocacy in every area. Broad participation of users through equal opportunities employment and service delivery practices. Users involvement in the planning, running and evaluation of services. A policy to ensure that it is safe for users to get involved. Users should train professional workers. Health service providers should give practical commitment and provide resources for user involvement.

Users are involved in MIND through formal structures. At least two users must be on the executive committee of each local MIND group and MIND's national consumer network. About a quarter of MIND's staff define themselves as users.

S.T.E.E.R

S.T.E.E.R Mental Health Organisation provides support, training, education and employment for people with a mental health disability. They also carry out research into mental health issues. STEER undertakes research, which is then used to design their mental health services.

This group is a partnership between people with primary and secondary experiences of mental health difficulties. They are also in

partnership with a range of organisations and Government/Statutory bodies. They also meet with other mental health organisations on a regular basis. The management committee consists of 60% users.

Involving Children and Young People

It is deemed an ongoing struggle to involve children and young people in the planning, monitoring and evaluation of health services. (David Wales 1993). Wales 1993 suggests that if we are to be effective communicators, which includes listening as well as talking, we must be able to use reference points, which relate to the lives of children and young people. The way in which we ask for young people's involvement and the context in which we ask it is important.

It was found that that young people respond differently to surveys on their needs in the context of school than they did on the streets (David Wale 1993). It was felt that we need to be sensitive and creative in the methods of consultation that is used.

Children's Services Planning (CSP)

In 2000, the Children's Services Planning (CSP) looked at the services for children and young people with a disability. The CSP decided that a very important priority would be to find ways of involving children and young people with disabilities in the planning of services for the future. (Kernohan 2002) The key issues that were revealed were

- Time is needed for capacity building.
- There is a need to get real (be pragmatic).
- The public sector is not a lead in child participation; the voluntary sector has a more developed user-involvement approach.
- There is a need to start with involvement in planning individual care, before becoming strategic.
- Use advocacy as appropriate
- Older children who are frequent service users are more likely to respond than younger children who don't use the system.
- Needs assessment requires user participation
- Different types of condition/disability require different approaches.
- Information from routine care can inform strategy
- Feedback is possible by survey, suggestion box or complaints system.

Fermanagh Shadow Youth Council

Fermanagh Shadow Youth Council is an initiative that involves young people. The Current membership of the Shadow Youth Council stands at 29. The young Councillors sit in the council chamber and Shadow the Senior District Council, debating issues and involving younger people in the local democratic making process. Councillors are frequently approached by statutory and voluntary organisations seeking a youth perspective. All information received by the office is summarised in monthly meetings. Feedback is minuted to all members for circulation. One of the Youth Shadow's main objectives

is to give young people a voice on local issues and allow them to take action, which transforms their situations, and the relationships between young people and the rest of the community. It also aims to enable the council, other statutory bodies, community and voluntary organisations to consult on the effectiveness of services provided for young people.

In the first two years of the Shadow Youth Council's existence over 70 requests from a variety of sources for involvement and expression of interest was received. Some of these were, The Northern Ireland Human rights Commission's consultation on "Bill of Rights", Western Area Children and Young people's Committee, re vulnerable young people. It is recognised that the actions and reputation of Fermanagh Shadow youth Council is growing and is driven by a culture, which is including and valuing the views of young people in society.

Learning Disability

People with a learning disability have usually either been separated from the wider community or lived with their families into adulthood. (A Fair Chance 2002). They are traditionally people who have had things done to them rather than done with them. The majority of people with a learning disability would like to live complete lives in which they are part of the community, with the same choices as able bodied people in areas such as work, health care, housing and adult education. Some people with a learning disability are able to access community life unaided but most will need some assistance to

engage in their particular interests and pursuits. It is therefore important that service providers in the statutory, private and voluntary sectors provided support so that people with a learning disability can participate in the planning and delivery of the services that they receive.

Oxfordshire Learning Disability NHS Trust

Oxfordshire Learning Disability NHS Trust provides a service for people with a learning disability, mental illness and challenging behaviour health support. This service is deemed an example of best practice as it provides a flexible service over seven days to people with a learning disability and mental illness who have a history of erratic and non engagement with health and social providers. They also have joint working with individuals and other teams in developing person care plans that enable the person to lead a better quality of life.

LEAD/A Fair Chance/Report on Consultation Exercise

A wide range of issues were addressed during the consultation exercise, including; daytime services, opportunities for employment, adult and continuing education, leaving school, the importance of self-advocacy, bullying, leisure opportunities, support and going to the doctor, the hospital and dentist.

It was found that more opportunities to develop skills in speaking out need to be developed. The need for choice, independence and respect for people's rights were constant themes that arose.

It was found that in order to have meaningful consultation with people with a Learning disability that the following issues would need to be addressed.

- Clear expectations about the aim of the events, and what can and what cannot be achieved.
- A shared commitment to the underlying principles.
- Effective partnerships, with all partners recognizing and playing to their strengths.
- Clarity about the roles to be played by service providers, supporters and carers.
- Detailed briefings for facilitator
- Accessible information materials with clear and consistent use of symbols and pictures
- The testing out of all materials, including the event title, with people with a learning disability.
- Access by all delegates to information beforehand, either directly or through supporters.
- The use of accessible venues with a good track record for inclusion of people with a learning disability.
- Identifying any additional needs in the application process and offering support, when necessary.
- The use of a number of venues across Northern Ireland, rather than one large venue, to encourage wider attendance.

- Make sure that transport and other support is available.
- Consider the timing of events, taking into account the arrangements of the service providers.
- Enable people with a learning disability to have a high profile at events as supporters and speakers.
- Encourage people with a learning disability to talk by facilitating small groups and ensuring adequate support.
- An independent facilitator and control over what is recorded gives delegates the confidence to speak out.

There was general agreement amongst delegates that health and social service's provide good support for them as they undertake to build meaningful lives and look for citizenship. However they also felt that there was room for improvement.

Ethnic Minorities/Irish Travellers

Travellers are a small indigenous minority, documented as being part of Irish society for centuries. Travellers have a long shared history and value system, which make them a distinct group. They have their own language, customs and traditions.

Travellers health is significantly worse than the health of those in the settled community. As travellers are a distinct cultural group they have distinctive health needs and require special consideration in the health service.

As part of an initiative to involve travellers in the planning and delivery of the health services that they receive, Pavee point in partnership with the Eastern Health Board (Southern Ireland) have developed a primary health care project. Part of this project involves training Traveller women to work as health care workers in their communities. Other traveller support groups around the country are currently replicating this model.

Traveller Women

The issues effecting Traveller women have always been an important part of the work of Pavee Point and a number of initiatives have been piloted that have specifically targeted woman.

Lack of access to basic facilities has a direct negative impact on Traveller women because of their domestic role. There is much opportunity for direct discrimination when woman, on behalf of their families, broker with settled service providers.

Ethnic Minorities/General

Involving users/improving the delivery of Health care. A report on How Leicester Royal Infirmary NHS Trust worked with black and minority ethnic communities to draw up a service improvement action plan. The report sets out the lessons that were learnt.

A wide range of issues emerged along with suggestions about how to address them. Some comments, not surprisingly, were about waiting lists, clinical treatment and other issues that are likely to be relevant to all patients. Some of the most frequently raised concerns were:

- Interpreting and translation – Health and Personal Social Services providers would need to acknowledge that many people cannot read or write in English.
- Staff attitudes. Some perceived staff as rude and unfriendly- Training in customer care would help.
- Food - the hospital needs to address issues of choice, quality and information.
- Cultural awareness - Hospitals should consider providing common prayer rooms and having more flexible rules for large families.
- Complaints and comments - Fear of victimisation is strong in certain communities - hospitals need a system whereby people can put their views anonymously, in their own language, in writing over the phone.

About two years ago the hospital set up a successful “Visiting Health Project”. Cantonese speaking nurses provided an out patient service at the centre. They advised people when to visit the doctor and went with them to surgeries and hospitals.

Another idea was to provide translated videos on particular health matters (as an example, a video with a Cantonese soundtrack on

breast cancer screening produced by the Glenfield hospital had been well-received).

Out of the Shadows/Action research Report into Families, Racism and Exclusion in Northern Ireland

The research documents the experiences of young people and mothers with young children from the Chinese, Indian, and Pakistani and Traveller communities in the areas of health and personal social services, social security, education, training, accommodation and policing. More specifically it examines the impact of racial discrimination on statutory service provision for the four largest ethnic minority groups in Northern Ireland.

A number of key recommendations were made in general.

There is a need to encourage inclusion and democracy by engaging ethnic minority community organisations in the earliest stages of the decision making process. Regular and close consultation is needed. Information strategies should be developed to keep ethnic minority communities informed of the availability of services, where to obtain services and who to contact for more information. Information would need to be available in the suitable format. It is equally important the dissemination strategy is developed to ensure that information reaches the targeted populations. It is also critical to monitor the process to ensure its effectiveness. Potential ideas include outreach

workers, translated leaflets, videos, regular briefings, or surgeries in community centres.

- It is important to identify key named people within statutory agencies who are responsible for anti-racism and ethnic minority provision. If this member of staff leaves, the responsibility should be passed onto another person. This should be a policy objective of an organisation.
- It is vital that any policies and services targeted at ethnic minorities are monitored for their uptake and effectiveness. This will be critical for future policy response.
- Alongside the importance of monitoring, it is vital to recognise the importance of research.
- It is vital to ensure the provision of interpretation through identification of language needs of service users. This could be achieved by developing lists of professionals trained for the job, whose human resources could be pooled. It might be possible to purchase interpreting services through community centres.
- It is important to develop ongoing training for staff, practitioners and policy planners of service provision in anti-racism and anti-discriminatory training. As well as cultural awareness training.
- It is critical that ethnic minority strategies are properly resourced.

None of the above recommendations will be possible without a resourcing commitment. Without a guaranteed funding commitment,

there is unlikely to be any meaningful change in the experiences of the statutory sector for ethnic minorities in Northern Ireland.

Sensory Disability/Talking Sense

Sense has always been close to its users. Founded by families as a support group for others with deaf/blind children. For the past four years, Sense has been trying to find ways of involving the end-user more closely in its affairs.

Sense Usher services are finding ways of involving people with Usher syndrome in their work, both as volunteers and providers of their own services. The volunteers help with administrative support, public speaking on behalf of Sense, data analysis and report writing.

It is recognised that consultation has to be on a one-to-one process for many of the people who use the services. For residents of Sense homes, user involvement means, first and foremost, enabling users to make choices-such as what to eat and where to go on an outing. In some homes, staff are now encouraging residents to say what member of staff they wish to work with. Advocacy is another step in the direction of giving users a voice. Advocates play a vital role in the lives of some of Sense users.

Major decisions affecting policies and directions are approved by Sense's council. Recently a deafblind person was elected to serve on the council. For many within Sense, involvement for service users

means providing opportunities for people to contribute at whatever level they can and wish to do so. It also means finding the balance between the needs and rights of congenitally deafblind people and those who acquired deafblindness. For some Sense users involvement means choosing what to do today. For others it means knocking on the doors of Parliament itself.

Woman

Positively women are the only national registered charity offering peer support - support for women living with HIV by women living with HIV.

Positively women provides:

- Peer support and Advocacy
- Crèche facilities and therapeutic services for children affected by HIV
- Information and advice
- Training and Volunteer opportunities

The organisation remains strongly committed to the ethos of peer support and empowerment.

Peer Support Project

Positively Women's Direct services team provide culturally appropriate peer support, advice, information and advocacy for

women living with HIV across Britain. All Direct work with service users is carried out by women who themselves are HIV positive and therefore can relate to service users' needs and concerns.

Children and Family Service

Positively women provides a range of support services for children and families affected by HIV, including a youth club for teenagers affected and infected by HIV and free registered childcare facilities. Support for parents include advocacy work and information sessions on issues such as treatments for HIV positive children.

Community Involvement Project

Positively Women's Community Involvement project works to improve service user consultation across the HIV sector and promote the mission of Positively Women.

Carers

Many carers see consultation as a process, which considers them as one element in the care package for their relative or friend, to be topped according to the availability of other services. They sometimes feel that their own rights as individuals are overlooked. (Barbara Poole 1993).

Many carers can be good advocates on behalf of their relative or friend. If professionals listen to carers and regard them as partners, the service they offer to the user is more appropriate and successful. Carers' rights should also be respected. First and foremost, carers have the right to be treated as individuals who are entitled to live their own lives. This should include deciding not to care, if that is their choice. Professionals need to be sensitive to the requirements of carers such as time and place, their need for confidentiality, and help in developing skills that some carers require. Carers should be paid for their time in the same way that professionals are.

Some carers are anxious that in speaking up about poor services or lack of services, they may be penalising their relative or friends.

Some carers need training to help them develop the skills necessary for consulting and negotiating effectively. Many carers are elderly, some have given up paid employment and have been caring for many years. Offering carers the chance to develop their assertion and negotiating skills provides a wider range of people with the ability to speak up about their choices and to take control over their own lives.

It is very important for professionals to listen to both carers and users, and recognise their different needs. Users and carers may work in one partnership but their right is to be treated as individuals.

HEALTH AND PERSONAL SOCIAL SERVICES PROVIDERS QUESTIONNAIRE RESULTS

Involvement

All respondents involved service users in the planning and delivery of the health services users received. Involvement of users is addressed by these organisations in a number of ways and by a variety of methods. Methodologies employed ranged from, one to one interviews, questionnaires, focus group discussions, reference groups, patient's councils, Ad Hoc surveys, newsletters and publications and complaints procedures. The type of method used depended on the client group, e.g. young people, people with a learning disability, and people with a physically disability.

Examples

User committees are the most popular method employed by Health and Personal Social Services providers surveyed to involve users. A large number of respondents have also developed a multi-agency approach. It was found that the community development approach has brought a wide range of staff and users together in a joint planning exercise in a number of the Health and Personal Social Services organisations questioned. This has enabled them to work in partnership with one another to discuss the planning and delivery of

new services and has also aided the development of user forums and user groups.

One to one interviews were seen to be the best way to involve people with learning disabilities by some organisations while others held user and carer led seminars. They believed that this generated creative and constructive ideas about involving users in the planning, and delivery of health services.

Training needs analysis for users and carers have also been carried out by a few of the organisations. This was to ensure that user and carers' health issues are kept to the fore, to ensure that their involvement is effective and to make public services more responsive to users and carers' needs.

Commitment to public involvement was outlined by other organisations that have developed public involvement policies.

Setting policies to users needs was felt to aid in the development and delivery of better services.

It is clear by the responses from all the Health and Personal Social Services providers questioned that they feel it is very important to include and involve users in the planning and delivery of the health services they receive. The vast majority of respondents believed that in order to be responsive to users they must be involved.

Involving users is said by some Health and Personal Social Services organisations questioned to make for good decision making as users are felt to be the experts in their particular field. Others felt that by including the user there would be a reduction in costs to the health service providers, as they were more likely to get it right the first time round.

Improved communication between the user and the provider was said to allow for easy evaluation. Evaluation of the effectiveness of service planning and delivery was said by one respondent to be incomplete without the views of the participants.

On further analysis however it was found that out of the 100% of organisations who involved users and who believed that it was important to involve users, only 29% were satisfied with the extent that users were involved, while 46% of them were unsatisfied. (See appendix 7). The organisations that were satisfied were organisations that were established specifically to represent the interests of users of Health and Personal Social Services and the majority of their work involves the user.

The majority of Health and Personal Social Services organisations questioned believed that there was no room for complacency, and they believe that there is still room for improvement. Most Health and Personal Social Services organisations in this study are continuing to seek new and innovative ways to involve service users.

Best way to involve the user

All of the organisations questioned, agreed that there was no one best method to involve service users. It was suggested by some that it depends on the area at hand and the user population e.g. Focus groups, questionnaires, young people or old, etc. It was suggested,

“By analyzing the composition of the user group and ascertaining what their requirements are, we can develop optimal tools of involvement. We need to look at the best support network possible e.g. childminding facilities, disabled access, free transport etc”.

To a large extent respondents suggest that users need to be involved from the outset, and that there needs to be structures set in place to check on the measures used. It was suggested by a few organisations that the best way to involve users was for Health and Personal Social Services providers to set targets in relation to user involvement with specified time frames.

It was also mentioned that it is important to remember that user involvement is a two way process which is about supporting and training users to be involved in participating effectively, but it is also about organisations developing inclusive user friendly systems as well as supporting staff to involve users.

“Using accessible language, looking at formats of meetings, ensuring users are supported when attending meeting. Trying to make sure

that there is more than one user involved in a meeting/project. Resources are essential to involve users in a meaningful way e.g. providing travel expenses, care support costs etc”.

Trust and openness was a key issue for some to get users involved, while the training of staff, training of users and carers was a key issue for others. The suggestion of training for those who wished to be involved was done so to ensure that user involvement was meaningful and maximum benefit was gained by their inclusion.

It was also said by a few Health and Personal Social Services organisations that users can be instrumental in accessing resources, developing new roles and new services, which in turn challenges Trusts and Boards to regularly improve services.

“Users have rich expert knowledge”.

Others Health and Personal Social Services providers suggested that there needed to be a shift in the culture of some organisations, and suggested by including users in decision-making this could be accomplished. One respondent announced that,

“It is necessary to change the mindset of the professionals. By involving the user it will help to bridge this gap”.

Benefits to Involving Users

A better understanding of user needs was the most prominent response to this question followed by a more focused, efficient and effective service being created.

“Help keep services focused to meet service users needs, while helping to access resources”.

Fewer complaints was also seen to be another benefit of involving the user by some organisations, which they believe leads in turn to better decision-making, and improved staff moral. Involving users also helps Health and Personal Social Services organisations meet its statutory requirements, while also helping to develop relationships with service users and the community. This was suggested by some to lead to a healthier and more confident population.

“Through their own inclusion, services will be tailored to their requirements and therefore, we can provide a more responsive service by incorporating the professionals’ expertise, the clients’ needs and a variety of experiences, views and opinions.”

Barriers to Achieving User Involvement

Lack of understanding, lack of resources, and bureaucratic inflexibility was seen by the majority of respondents as the main barriers of achieving user involvement.

“Need for greater access and support. Access extends from physical access to the availability of structures and arrangements that enables and encourages peoples’ involvement. Support includes support for personal development and skills development. Practical support (information in a variety of formats, advocacy, payment of expenses), and support to get together and work in groups.”

Consultation overload was seen to be a big issue with a number of respondents due to the large number of reviews the Health and Personal Social Services organisations have undertaken lately. Others also considered negative attitudes of some of the Health and Personal Social Services staff and of some of the service users and carers as a barrier to achieving user involvement.

Ways Forward

Development of policy and implementation of policy to involve service users was the main way forward for some Health and Personal Social Services organisations that responded, while a continuous relationship with other organisations such as a multi-agency approach; a community development approach was seen to be the way forward for others. As mentioned previously in the barriers to user involvement it was suggested that in order to truly involve the user, thought must be given to the time, location, venue and transport arrangements for the particularly user group in question.

“Design the means of involvement around the specific user group and cater for their needs.”

Training and support for users and staff was seen to be another way forward to keep users involved and to ensure that involvement is effective. Highlighting examples of good practice through conferences, articles, papers etc. were other suggested ways to include service users.

Providing feedback on all occasions where users have been involved was considered by most to be a very important way to ensure ongoing user involvement, to help develop a continuous relationship between users and Health and Personal Social Services providers.

“Giving feedback to users to ensure that Health and Personal Social Services are not just paying lip service.”

Commitment from organisations at a strategy level was identified as being a good way to include service users and to keep them involved. Open discussions to establish real channels of dialogue were also seen to be a progressive move rather than paper exercises.

All organisations felt that involving the user would enhance their services.

“It ensures more responsive services and helps to keep the providers of services in touch with the population they serve.”

It was felt by a number of the Health and Personal Social Services organisations questioned that users are best placed to identify gaps that may have been overlooked by them. Involving users was seen to provide valuable experience and expertise when planning and delivery Health and Personal Social Services.

Evaluation of services was said to be very important to the Health and Personal Social Services questioned. Evaluation on the effectiveness of involving the user with the responding audience was carried out in a variety of ways, such as reduction of complaints, feedback from questionnaires, focus groups etc. Some organisations suggested to have outside monitoring agencies to evaluate services in order to ensure that targets and standards are being met in relation to user involvement.

“External evaluation and community forums were very positive. Effectiveness is a better service.”

However on saying this a substantial number of Health and Personal Social Services organisations that were questioned did not have any evaluative structures in place which would suggest the need for further development in this area.

“Using services is by its very nature subjective, impacting on the quality of peoples’ lives. The same quality and inclusion that are the basis of service provision must be fundamental to the planning process as well.”

RESULTS FOR COMMUNITY AND VOLUNTARY GROUPS AND INDIVIDUAL QUESTIONNAIRES

Involvement

Responses to the questionnaires from the Community and Voluntary sectors and individual parties found that there was quite a range of services provided to the user. These included, providing support to people with MS, drop in services for youth, youth councils, services for the disabled (sensory, mentally, learning and physical). Community development and health work for woman age 26-59, older people age 60+, young people aged 4-25. Education programmes for parents of children from birth to five years, cancer support services, older peoples programmes, support programmes for ethnic minorities, and support for woman and children who were victims of domestic violence.

The services were carried out in a number of ways and by a variety of methods. Methodologies employed included information and advice such as one to one interviews, newsletters, and telephone helplines. Alternative therapies, such as yoga, Qui Cong and physiotherapy

exercise sessions were also provided. Training programmes, education and health promotion, such as computer skills, confidence building and capacity building programmes Counselling services, advocacy services, child protection and family support services were also provided. Interpreting and translation services, residential care, carers support and supported housing are also included.

Ways to Involve the User

Many of the organisations questioned included users in the planning and delivery of the services they received. (92%), 2% of respondents didn't know if they involved the user while 6% of respondents were interested individuals.

Ways in which they involve users include; sitting on executive and management committees, the recruitment of staff, actively involved in fundraising events and also part of user forums. Feedback from users and requests for training were used to inform future programme development in some of the organisations questioned. Users were also involved in training and are part of community consultation sessions, either by focus group discussions, one to one interviews, completing questionnaires or in support group meetings.

One particular organisation attempts to apply the skills of the user that were developed at their centre, to help with the delivery of courses and services.

A substantial number of respondents felt that users have a direct influence on planning and in the delivery of their services, with the majority of users being members of the management committees. Other users have influence through annual evaluations, inspections and complaints procedures.

“We have the highest regard for users’ opinions and influence. It is the user we are providing the service for and it is their opinions that matter the most.”

Another respondent felt that because they do not provide a service as such, they as an organisation believe that they influence the planning and delivery of health services provided by Trusts and Boards.

A number of the groups questioned felt that the users of their organisations didn’t have as much influence on the planning and delivery of services as they would wish but they hope to change this in the near future.

The groups questioned employed a number of methods of evaluation. These included ongoing consultation, quarterly, six monthly and annual meetings with users. Evaluation forms, informal feedback on a one to one basis or in feedback forums, external and internal audits, questionnaires, and monitoring and evaluation days where people are invited to give their views in small groups. Some organisations have standards written into organisational policy, and reviews include an audit of user involvement standards, while others have evaluation

surveys. A few of the organisations questioned do not have any formal evaluation mechanisms in place.

94% of respondents felt that it was important that health service providers should involve users in the planning and delivery of health services, while 2% felt it wasn't important and another 2% were unsure.

Some of the reasons that respondents felt it was important to involve users were,

“Health service providers can benefit from hearing the views and experience of users. This includes both positive as well as negative views.”

“Users can provide insight into gaps in service provision that busy professionals may overlook.”

The importance of involving the user in the planning and delivery of health services was said to be of benefit to the provider by the majority of respondents. Users were seen as the experts, therefore it was felt by including the user in the decision making process individual needs can be addressed and shortcomings in the service can be dealt with in a more effective way.

One particular respondent also said it was important that health service providers involve service users in the planning and delivery of health services as,

“Users can help allocate resources accordingly as well as help to raise awareness of the services that are available. If users are involved they will be familiar with the end result.”

From the question,

Are you satisfied with the extent that health service providers involve users in Planning and in the Delivery of health services?

Responses varied. 21% of those questioned were happy with the way health service providers involved the user.

“Yes, I feel that there are steps being taken towards involving the user, which will enhance better communication. People are not always aware that their views are wanted.”

“Trusts are doing the best they can.”

“We feel that visually impaired people are sufficiently involved in service delivery and planning. Rural isolation can make accessing involvement groups difficult not impossible.”

46% were unhappy. Some responses are listed below.

“No, as a lay health worker it is difficult to think of any user involved in planning/delivering of services by the health service providers.”

“Current planning is very much based on the professional knows best mentality and tends to downgrade or dismiss the views of users. Not enough is being done to secure and use the views of the users. The language used by professionals creates an intellectual barrier to the involvement of users.”

29% of respondents were unsure of the extent that users were actually involved, while the remaining 4% did not reply to this question. It was felt by a number of organisations that users,

“Don’t really know how users are consulted or involved.”

“Providers would need to map out what extent the health services involve the user.”

A large number of respondents (48%), were largely unsure that the views of users actually influence the services that they receive from health service providers.

Comments made were,

“Not well enough informed to know how the views of users have influenced decisions in the past.”

“Difficult to answer. People with a learning disability need advocates to represent their needs. The small number of adults with a learning disability who can articulate their views can not represent adults with a special need.”

35% of respondents are not satisfied that the views of users will be taken on board,

“Our community in the Northwest has not been involved in giving their views of the service provided by the health service.”

“It takes too long a period from the time the user is consulted until changes are implemented on the ground.”

The remaining 17% of those questioned were satisfied that the views of users influence the services they receive from health service providers.

“Yes I am satisfied, users need to be made aware of the restrictions of involving the user. Such as time, money and other organisational constraints.”

“Yes, as long as action is taken and user consultation is taken seriously and not as a token gesture.”

Ways to Involve the User

The majority of those that responded felt that there was no one best method to involve users in the planning and in the delivery of health services.

A number of methods were explored these included; e-mail and Internet access. Consultation days, using existing local health and social care groups but improvement on equal mix such as men/woman, catholic/protestant etc. so that views from a number of perspectives will be obtained in order to get services right, partnership working.

Focus groups, user forums, user involvement training, interviews for service users to enable them to be involved in the monitoring and evaluation of health services and also by the distribution of questionnaires in health service waiting rooms were seen to be ways to involve the user. An information help line was also suggested as a means to get the user involved alongside information being in the appropriate format for the specific user group or individual. Direct contact or a point of contact for direct feedback was suggested to be another method to get the user involved.

All and all it would seem by the responses given that there is a need for a clear framework to make users aware of how they can be involved in the planning and delivery of Health and Personal Social

Services and how service user involvement influences the health services they receive.

Others that were questioned said that health service providers would need to look at themselves if they really want to learn. Change and partnership is needed so that users will know what level to negotiate and not regard involvement as a technical exercise.

One respondent suggested,

“There is no easy way to do this, rather a process of openness, honesty, trust and respect, which will prepare the ground for opportunities of working together.”

Benefits to Involving the User

The views of users are important, and the benefits are numerous according to the responses given to the questionnaires. The benefits to involving the user in the decision making process included, a more effective and most importantly cost-effective health service, less abuse and more genuine usage of the health services if the users feel involved in decisions.

“Empowering the user leads to feelings of more responsibility on the user for the service to work when they have an opportunity to put their views across.”

Users are better informed about existing provisions if they are included; therefore services are targeted more effectively to users needs.

Reductions in illnesses/hospital admissions etc was also a perceived benefit along with less complaints which was suggested to lead to a more cohesive service with quality improvement.

Barriers to Achieving User Involvement

A potential barrier to obtaining user involvement was seen to be that of apathy amongst the users of Health and Personal Social Services and Health and Personal Social Services providers. It was suggested by a number of respondents that users often feel that they are over-consulted and that there are no tangible results to be seen from previous consultations.

Outdated and entrenched attitudes at senior management level down to the staff that are delivering the services were also seen as a major barrier to involving the user.

Other perceived barriers were that of training and capacity building for the service user. Users may feel that they do not have the necessary skills or the confidence to be involved in health service decisions. Accessibility to information, resources, locations and

timescales were also seen as major barriers to including the user. One respondent felt that,

“The extent to which service users participate in the design of services is more usually described as a continuum. At one end of the continuum the relationship between the service user and the service provider centres on the communication and sharing of information. The relation then progresses through the consultative stage to full partnership (which involves shared decision making and ultimately to delegated control). This is the barrier.”

Ways Forward

Openness, transparency and commitment by health service providers were seen to be the best way to ensure ongoing user involvement by a number of organisations questioned. Partnership working between statutory and voluntary bodies encouraging users to be involved and ensuring ongoing user involvement was suggested by others.

One particular respondent suggested that,

“A system should be established that can be sustained locally and ensure feedback to all parties to demonstrate the benefits of user involvement, alongside nationally co-ordination to maximise impact of useful links.”

Overall the responses to the best way for Health and Personal Social Services providers to ensure that user involvement is ongoing included; a change in the culture of health service providers, service user training, service user forums, focus group discussions, shadowing schemes, user led research on openness to constructive criticism. Training for health professionals, adverts in community magazines, local newspapers and posters were also other suggestions.

It was said that Health and Personal Social Services provided would need to put funding into user groups/reference groups in order to inject some balance of sustainability for the future, alongside providing the space, the expenses, and by completing regular evaluation of the work and services that are taking place.

“Responding to issues identified by the users, even if the response’s are not what users would want, also break down the barriers at senior management to community development.”

“This is a question with a lot of answers and different levels, but ultimately there has to be a commitment right at the top to real user involvement that has a definite impact on how things are done. Otherwise much of what might happen is only lip service to the idea of involvement.”

HEALTH AND PERSONAL SOCIAL SERVICES TELEPHONE INTERVIEWS

Fifteen telephone interviews were carried out with Health and Personal Social Services providers who identified initiatives and programmes that they feel work for them. However, because the questionnaires gave in-depth information in the first instance, there was not a lot of new information to be gained.

All programmes contained some element of user involvement, such as user representation on Board's and Trust's planning groups, involvement of users and carers throughout all care programmes in assessment of their needs, reference groups, and patient's councils etc.

It was felt by a number of those who were questioned that partnership working was the best way to get users involved, they felt that community liaison officers were best placed to identify with users. It was felt when users identify with a particular person a relationship of trust is established and more objective assessments can be made.

All of the Health and Personal Social Services providers questioned stated that involving the users enhances their services. Improvements in service provision, therefore is a clear indication of the significant effectiveness of this approach. It also provides

invaluable insight into problems or issues that are faced by the user. Although there is recognition that a lot of good work is being carried out by all of the Health and Personal Social Services providers questioned to engage with users there is still room for improvement.

FOCUS GROUP DISCUSSION RESULTS

Young People

In an Ideal world, what would you expect true User Involvement to mean?

For this group of young people it was suggested that in an ideal world user involvement would mean that everyone's views are listened to and taken on board.

“The views of different groups not just specific groups of people and individuals that appear to be interested in the health services”.

On asked to identify what services Health and Personal Social Services provide only a few were identified. These included, GPS, Hospitals, old peoples homes, Dentists and home helps.

This group felt that a set of guidelines should be set up for youth and young people in order for them to be involved. They also felt that

health services should be defined to give an understanding on what is available and made appropriate for the user group.

One member of the discussion suggested that,

“Information should be made user friendly and made readily available.”

What sorts of decisions about health services do you feel you should be involved in making? - Decisions about service planning, service delivery etc.

As this group of young people are all under 18, they felt that in order for them to be truly involved in the services they receive, information should be given directly to them. The majority of the young people questioned felt that doctors, dentists, health care professional's etc. often talked over them to their parents or guardians.

These young people felt that they should have more say in how resources were allocated in health services, especially where emergency health services are concerned.

One young person expressed concern on hospitals having no beds available when there is an emergency, which can often lead to life-threatening situation.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

The majority of participants in this group discussion felt that user panels were a good idea, however it was agreed that some young people would need training in order to take part in this type of committee or panel.

This group felt that there should be some confidence building exercises. There was also the suggestion that panels should consist of one large user panel with a number of sub-groups in order to accommodate as many users as possible. Any information received could be then fed through from the main group to the rest of the subgroups.

Are there any specific issues, which would prevent users such as yourself either being involved in a users Panel, or making your views known? - What are they?

Some of this group felt that timing was a problem for young people. It was felt that many user projects or consultation with health services happened during school hours, which meant they either could not attend or would have to have a day off school to give their views and opinions.

The expense of travelling to and from meetings was mentioned as another barrier to getting involved for this group. All of the people in this group are still at school and do not have the resources to finance themselves; therefore most of their parents pay expenses out of what some considered to be already stretched budgets. The entire group agreed that expenses should be paid.

When they are actually involved, this group felt that the best person to chair a meeting or committee should be young people themselves. The structure of the committee on suggestion of this group should include Health Board representatives, at least one person from the nine categories, and one person for back up when needed.

At least a weeks notice should be given for meeting, agendas in a “user friendly” format circulated at the same time. Venues should be alternated in order to accommodate all members of the user committee.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

Suggestions made by this group were:-

Staff should be trained to develop listening skills in order for them to fully understand what is being said. Training skills should also be

given to users to instil confidence in being involved and to help with capacity building with Health and Personal Social Services providers.

Notice boards in schools could be used to inform young people of any projects, meetings etc in relation to the planning and delivery of services. The group in question also felt that websites were another good way to get information across. However some members of the group felt that the websites would need to be colourful and eye catching with possible photographs and pictures to appeal to younger clients.

Leaflets in waiting areas or handing leaflets out free with prescriptions in GPs, dentists, hospitals etc. were another way to help get the young person involved.

“Often you are bored in the waiting room and if that was all there was to read then it would be read.”

Local newspapers, regional newspaper were suggested as other ways to inform this group of users. Local radio, T.V campaigns, community billboards etc.

It was suggested that in order to ensure that user involvement takes place all work already done should be reviewed and evaluated. Good practice should be then shared. Plans should be written up and updated continually. Existing groups should be used, and when any

members leave they should try to ensure that there is an overlap between new people coming on board and the old member leaving.

Workshops and conferences were suggested good methods of getting the user involved by this group. Networking with other groups to create partnership working to give a greater spread of ideas and opinions was also felt to work.

Alongside these it was mentioned when the likes of Focus groups and meetings take place the person facilitating or chairing the meetings must have some experience of carrying these out as sometimes people on boards and groups have their own agenda and are not willing to listen to anyone else's views and opinions.

Comment cards were seen to be a useful means to gaining feedback, but it was suggested that they should be completed before leaving the meeting as immediate feedback is needed. An experience chair or facilitator will be able to keep people focused on the issue at hand.

“If allowed to complete later more times than enough people forget about them and there are not returned”.

Physically Disabled

In order for them to say what they would expect true user involvement to mean in an ideal world this group felt that they would firstly need to provide a definition of what user involvement meant to them.

One member of the group explained that he felt that there were two areas within “user involvement”. These were,

1: User involvement on an individual level, such as the direct engagement of doctors, occupational therapists etc.

2: User involvement at a policy level with the direct engagement of users in the planning and delivery of services.

The entire membership of this group agreed with this definition. However it was felt that it would be useful if Health and Personal Social Services providers gave a definition on what exactly “user involvement” meant to them, in order to clarify if user involvement had the same meaning for both the user and the providers of services.

In an ideal world, what would you expect true User Involvement to mean?

One member of the group suggested what this would mean for them. They explained that this would mean that they would have more of input into their care and are more informed of the outcome of their care. They also explained that in order for this to happen there needed to be support systems put in place.

The majority of this group also felt that there was a need for Health and Personal Social Services providers to provide capacity building

programmes, it was felt that people with disabilities need training so that their involvement would be more meaningful.

“ There is a need for induction training for users so that they can take their proper place and have a proper voice”.

Others in this group felt that it was important for Health and Personal Social Services providers to keep the language simple and jargon free when consulting with users.

What sorts of decisions about health services do you feel you should be involved in making? Decisions about service planning, service delivery etc.

Some of this group has been involved with a number of user groups within the Health and Personal Social Services and because of this there was a lot of scepticism of what this project will achieve.

It was mentioned that the concept of user involvement has been disseminated over the past 4 years but the people on the ground are not seeing any direct change in services. This was said to be very frustrating for the people who are already getting involved. It was felt that Health and Personal Social Services providers should fit into Community and Voluntary structures that are already in place and are thought to work.

It was suggested by one member of this group that Health and Personal Social Services providers should fit into community and voluntary structures that are already in place and our proven to work,

“ Why should users have to fit into existing structures when they are obviously not working”.

“ We need action to see actual change, change has to be on the ground and not through consultation”.

All members of the group agreed on this. It was felt that existing structures are not working, as they have not created change.

It was also suggested that health professionals should be trained to fit in with existing community groups and projects as this group membership all believe that these people are the "true professionals”.

“ Expertise comes from the users and the carers”.

However it was also felt by another member of this group that alongside disability awareness training for professional there is still a need for health care providers to provide training for carers of people with a disability. This was felt to be very important especially for a carer who has a disabled child, as there are a number of issues that arise as that child is growing up.

A number of participants felt that they should have more input into their care and the care of a dependant and their involvement should be more than mere consultation.

Some respondents of the discussion felt that the process of involving the users is slow and bureaucratic, and they feel that it is still the Health and Personal Social Services providers that get the final say when decisions are being made and not the people on the ground. It was also felt by a few members that even though they are disillusioned with the idea of user involvement, and the way that health service providers include them, they are **NOT** afraid to get involved as they feel it may affect future services they receive.

The majority of those questioned feel that “user involvement” is just a PR stunt for the Statutory boards as by law they now **HAVE** to involve the user and this entire group feel that they are being used.

The majority of this group feels that they should be involved in strategic planning as well as in local planning. They all feel that they are the experts and that they have a wealth of experience to offer which is all too often taken for granted. Therefore they feel that they should be paid in the same way that outside consultants are.

One member of the group mentioned previous research that had taken place in the area of disability and user involvement. They talked of the findings and the economic savings to the health boards by directly engaging with the user.

“Resources are targeted and services tailored to meet the client groups needs, promotes sustainability”.

The same respondent felt that health service providers should support community groups that do not have the capacity to consult. They feel that there is a lot of good work being carried out by community groups who provide a service to the public, and who the Health and Personal Social Services have sought advice from in order to improve their services. They therefore feel that if the health service providers know that it is working for the community groups they should provide the funding to sustain these groups.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

The answer by one member of this group to this question was

“Useful to who? If it gets the board off the hook again then it wouldn’t be useful”.

To a large extent this group felt that a user panel that included all nine categories wouldn’t be feasible as they felt that there would be too many different agendas. It was felt that the composition of a user panel would need to be addressed before it could be established.

One member of the group said that they would like to know how such a panel would be structured, e.g. who the representatives should be, and who they would report to before they could say if it would be a workable way or not.

Multi-sectoral panels representing each of the 9 categories was said by another respondent to be a much more radical way of involving the user. Information could then be fed from each group through an elected representative to health service providers at every quarter. This would bring it down from the elite structure and make it more accessible and beneficial to the whole community.

Another participant in this discussion felt that there should be more than 9 members in a user panel, especially as there was a number of categories within physical disabilities, such as sensory and hearing disabled. They felt that 12 members of a panel would be a better idea so that all categories would be included.

It was also mentioned by a number of the participants that there is still a need for higher level commitment and change in attitudes.

“ A lot of information has already been given, and there has still been no progress in developing any concrete structures”.

“There is a need for more honesty, openness and transparency, there needs to be a culture change”.

Are there any specific issues which would prevent users such as yourself either being involved in a users panel, or making their views known? - What are they?

There are a number of issues that the majority of this group felt that would hinder their involvement in user panels. These included such things as the attitudes of staff,

“Often people with a physical disability are treated by health professionals as having a learning disability as well, we are often treated as if we do not have the mental capabilities to be involved in decision making”.

Many members of this group were angry and annoyed at how often this happens to them. It was felt by these members of the group that the abilities of people with a physical disability must be recognised and not be brushed aside by health service providers to enable them to have the confidence to take part.

Accessible transport, accessible venues, expenses being covered, jargon free language, providing training to have the confidence to get involved, were all considered to be important issues that would need to be addressed if a user is to be involved. Particularly for a person with a physical disability to be involved?

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

This group felt that they had answered this question previously. However it suggested that the use of focus groups, one to one interviews, (more qualitative approaches to gathering information), rather than the use of questionnaires was seen to be the best way of consulting with users.

It was felt by a number of those questioned that questionnaires can sometimes be interpreted wrongly and do not provide the in-depth information that is required.

Do you know of any initiatives/have you being involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these projects? What was poor about these projects?

Foyle Trust User Involvement Project

One member of the group felt that it was important to mention that although they recognise that there is a lot of good work being carried out, a lot more needs to be done.

It was felt that the major problem with the Foyle Trusts user involvement project was that only one member on the user panel has a disability. Therefore the majority of this group felt other categories were not being truly represented and their voices were not being heard.

However another participant felt that sometimes Health and Personal Social Services providers included people on user panels so that they don't actually speak out about services. Therefore rather than having their voice heard it actually prevents people from speaking out. There was a lot of mistrust about why the Health and Personal Social Services are actually involving users.

The members of this group felt that although they had built up alliances and worked with the board on a number of occasions, they felt that they are not being truly listened to as nothing concrete has been carried out to date. They feel that there is a real need to see direct results from previous involvement, otherwise no one will want to be involved in future projects. They feel that there is a need for action and not just talk.

It was also mentioned by one member of the group that sometimes Health and Personal Social Services organisations do not recognise the knowledge of local people and it is sometimes trampled on. They felt that Health and Personal Social Services organisations do not take on board individual expertise and experiences.

Advocacy was also mentioned as another way that people with a physical disability could be involved. However it was felt that advocates should not be employees of the health services, rather they should be someone from the community.

Older People

In an ideal world, what would you expect true user involvement to mean?

The older people in this group felt that they really didn't know how to become involved, therefore they didn't feel they could say what true user involvement meant to them.

What sorts of decisions about health services do you feel you should be involved in making? Decisions about service planning, service delivery etc.

A number of people in this group felt that they should have more say in their care. Some felt that they should be able to say how many hours a week they require home helps. A lot of the older people felt that there was a lack of communication between Health and Personal Social Services providers and themselves and that channels should be built into the care system so that they are consulted when decisions are being made in regards to them.

Do you feel that users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

For this particular client group a lot of them felt that user panels would not work for them. A large number of the older people have mobility problems, therefore are restricted on when and where they can go.

They felt that a better way to involve them would be for a Social Services representative to visit them at a time and location that is suitable to them, e.g. The Day Centre where they already meet once a week.

Are there any specific issues which would prevent users such as yourself either being involved in Users Panel, or making their views known? - What are they?

As mentioned in the previous question there is a restriction for the older people of this group getting involved, as there is some mobility problems. A problem was also found with communications channels. Apart from one member of the group this group didn't know how to be involved, as there are no specific structures in place to give people of this community information about the health services they receive. More consultation with themselves on a one to one basis or with members of their family was suggested. A newsletter delivered to each of their doors to give them information was also suggested. Communication problems also discussed were hearing difficulties, and language problems. Expense of going to meetings was also deemed to be a problem for this user group. Although expenses are paid in most cases it takes a while for them to get paid. It may therefore help if more immediate payment methods were in place.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

There is a lack of trust in the Health and Personal Social Services with this particular group. They feel that in the past no feedback was given when letters of complaint were sent into a couple of hospitals.

Feedback channels should be put in place to ensure that older people feel that their views and opinions are valued. Some felt that there should be a specific person to feedback complaints.

Some of the older people in this user group felt that older people living in rural areas are being left out. They feel that Health and Personal Social Services providers should give home visits to this group, as well as other older people who are unable to attend doctors' surgeries because of ill health or lack of mobility.

Do you know of any initiatives/have you been involved in any projects in the past, which sought to involve users in decision making? What has worked well/was good about these projects? What was poor about these projects?

No one knew of initiatives

Anything else?

Health and Personal Social Services should allocate more resources to older peoples groups, in order to sustain Day Centres. Money that they save in caring for the elderly should be given back in other ways, such as money for transport, day trips etc.

Personal care in nursing homes should be provided free. At present older people in nursing homes have their pension taken away from them and an allowance of £8 is given. The old people in this group felt that this wasn't enough especially if someone smokes.

T.V licenses should be paid for from pension age instead of over 75. Bus passes to be given to men at the same age as woman.

This group also recommended a new telephone system in doctor's surgery. The majority of older people in this group felt that the system in place was too complicated for them. A direct line into the doctor's emergency surgery was felt to be a good idea.

Learning Disabled

In an ideal world, what would you expect true User Involvement to mean?

First of all this group of people where asked to describe what Health and Personal Social Services meant to them. There were a number of answers. GPs. Hospitals, Dentists, Physiotherapists, Social

Workers, Dieticians, Day centres Occupational therapists, Speech therapist, Out patient Clinics, Psychiatrist services, e.g. cognitive therapy and Psychologists.

In an ideal world true user involvement for this group would mean that health services providers would look and see what's actually happening on the group for people with a learning disability.

The majority of this group felt that there was a lack of communication between the professional and the user who has a learning disability.

This group felt that they should have more input into the services that they receive. More channels need to be opened in order for them to be able to do this.

What sorts of decisions about health services do you feel you should be involved in making? Decisions about service planning service delivery etc.

People with a learning disability feel that they should be involved in planning the services they receive and also how they are delivered. The majority of this group felt that they should have input on issues such as the treatment, type of treatment they receive and for how long they should receive the treatment for.

One member of the group had received speech therapy up until primary school age. Treatment then stopped even though the person themselves felt that they still needed therapy. They had to pay privately to continue treatment.

Dental services were moved from one location to another without any consultation with another member of the group who was accessing this service. This group felt that it was very important for them to be included in these decisions.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

Even though this group was very confident in taking part in committees and panels, they felt that people who didn't have the confidence to give their views should be given training to enable them to be included.

The majority of participants in this discussion also felt that it would be hard for them to get their voices heard in a large user group. They felt that smaller groups or panels would work better for them. One participant suggested that the head of Health and Personal Social Services providers should come to them to gather their views and opinions in a face to face interview.

Are there any specific issues which would prevent users such as yourself either being involved in a user panel, or making their views known? - What are they?

The use of jargon sometimes used by health care professional would put the majority of people in this group off from taking part in discussions. This group felt that “user friendly language” would need to be used so that they would be able to understand what is being discussed so that they wouldn’t feel intimidated. The same was said for information about treatment. To a large extent participants felt that health professionals would need to be trained to explain information, conditions in “user friendly” language.

Information about any meetings should be made “user friendly” so that the information is accessible to people with a learning disability. Where possible it was suggested by a member of the group to pilot information with a few people first. The use of tapes to receive information was considered to a good idea for a few members of this group. Another member felt that when information to be discussed at meetings was unfamiliar to them they would need at least a week to familiarise themselves with the information. If information to be discussed was familiar to them then they felt it would be appropriate to discuss it on the night of the meeting.

The group was also in agreement that when they take part in a meeting they should have direct feedback from it and be updated about what is happening. A number of participants felt that it was very

important to receive thanks for taking part in group discussions or projects. This goes a long way in letting them know that their time and views were valued.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

This group felt that resources or lack of resources would need to be looked at. Even though most people in this group had a social worker assigned to them some had not had any contact with theirs for quite a while. There was an understanding amongst the group that social workers have large workloads, but they felt that there was not enough individual time to meet individual needs. Lack of resources also mean that people with a learning disability have to continually change social workers.

The training of Health and Personal Social Services staff was felt to be a good idea by the majority of this group to make sure that users are more involved in decision making in the future. The reason why they feel that staff needed training was the need to find ways for them to communicate better with people with a learning disability.

“Everyone has to have their say, sometimes we are treated differently, discriminated against because we have a learning disability”

“Sometimes we are talked over instead of talked to”

The majority of participants felt that Health and Personal Social Services staff had bad attitudes towards people with a learning disability. They felt they needed to find a more personal touch so that they are more approachable.

“It only takes two minutes to put a sticker on my file to let professionals know I have a learning disabled, when they see this they should treat me accordingly”

A number of respondents voiced concern about the lack of communication between Health and Personal Social Services staff. Different professionals often gave different diagnosis.

One participant has had appointments changed and because of lack of communication between staff members the blame for being late for an appointment was placed on them. Structures should be put in place in order to double check before staff start to victim blame.

Promoting and funding self-advocacy groups were suggested by the majority of participants to be a good idea to involve users in decisions about the health care they receive.

“Self advocacy groups have given people with a learning disability the confidence to speak up and stand their ground. Everyone with a learning disability should have more choice and scope in their lives”

Expenses were another issue that was discussed with this group. Most members felt that they should have their expenses paid in order for them to go to user group meetings. Travel expenses along with covering the cost of having to make the phone call in order to arrange travel, was mentioned by another participant of the group.

The majority of the group agreed that they felt it was important that Health and Personal Social Services providers helped with the funding of community and voluntary organisations like themselves. They felt that by being part of the Buzz group they had grown in confidence about being involved. Many felt that they would not be able to speak out about decisions in the health services that affected them if it was not for the group.

This group was also in agreement that the Health and Personal Social Services providers should help fund recreational activities such as residential for people with a learning disability. This is where people with a learning disability work with other groups, which allows for some capacity building.

Do you know of any initiatives/have you been involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these project? What was poor about these projects?

Camphill Community

Buzz Groups.

Nothing was mentioned about what was good or bad about these projects,

Anything else?

Talking in general about the health services they receive the large majority of this group had a number of complaints about the services. One participant talked of having to wait too long for GP appointments, and having to wait when they actually got to the surgery. The same was said for Hospital appointments.

Problems were also mentioned by another member of the discussion group who had to have blood tests carried out in the hospital, talked about blood samples going missing, then having a long delay between getting the blood tests until they actually received the results. Said that the long wait often made them feel anxious.

However some examples of good practice were also mentioned by a couple of members of the group. One participant said they had a very good relationship with their GP, and found him very approachable. Another had a good rapport with their specialist doctor, again he was

found to be very understanding and approachable and was very open and honest with them.

All and all this group felt that attitudes are changing within the Health and Personal Social Services, and things have improved for people with a learning disability. However it was still felt that there was a lot more to be done.

Chinese Community/Ethnic Minorities

In an ideal world, what would you expect True User Involvement to mean?

This group felt that in order for them to be truly involved, the language barrier would need to be broken down first. This entire group felt that a doctor of their own race or the use of an interpreter was needed within the Health and Personal Social Services. Ideally they felt that both should be provided.

What sorts of decisions about health services do you feel you should be involved in making? - Decisions about service planning, service delivery etc

The majority of this group felt that they should have more say in the times that they can see their GP's. They feel that there is a major problem with waiting lists, i.e. up to two weeks for an appointment. Also it was felt by some of this group, because of the language

barriers some of the people in the Chinese community feel that they are unable to explain to their doctor the exact symptoms that they are experiencing. For example, whether the pain they are feeling is either a sharp stabbing pain, a throbbing pain etc.

The Sai Pak community in Derry feels that it would help them if the health service providers contacted them about any decisions that are being made to enable them to inform the rest of the Chinese community in the area.

One member of this group felt the Western Board Area health services were behind some of the other board areas in the Northern Ireland when it came to the provision of services. Interpreters are already being provided by some health services, others have also opened a fold for the elderly Chinese community; they feel that more should be done to plan for the future.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

Some of this group felt that user panels were a good idea in theory, but do they actually work in practice? The majority of this group felt disillusioned with the system as they feel that no direct working has taken place. There is a lot of mistrust of the health service from this community. A number of this group has sat on user panels before but they feel that there is nothing being done. They have never had **any**

feedback from previous consultation; they have continually mentioned the same problems that continue to arise but feel that nothing is being done to reconcile these problems.

Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - What are they?

Language would seem to be the major barrier that would prevent these users been involved in user panels. A number of this group felt that there needed to be better communication between health service providers and themselves. In order for the Chinese community in Derry to be involved in user panels, meetings would need to take place at the beginning of the week and at mid-day as the majority of this community work late nights and weekends. They feel that training would be useful but more than anything they feel that consultation must be meaningful.

A large number of those questioned felt that the agenda for any meeting must be provided be in both English and Chinese and be received at least one week in advance of the meeting. Elected representatives from this community should be included on user panels.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

Same as before, use GP's of their own race, use interpreters. Be honest on what they can and cannot do.

Do you know of any initiatives/have you been involved in any projects in the past, which sought to involve users in decision making? What has worked well/was good about these projects? What was poor about these projects?

This group were not involved in any other initiatives and have found that a lot of information is coming from England but feel that there is very little done in Northern Ireland. They feel now that they have an influence in the health services in Derry due to the establishment of the Sai Pak community. They feel that they are a centre point for information and there should be better communication between themselves and the health and social services providers.

Anything Else?

In connection with the provision of services, a number of members in this group feel that something needs to be done in regards to GP registration. Some people in this group have been finding it difficult to get registered with a GP. Another issue that was brought to attention by a member of this group, was the use of medicine and drugs. They felt that some GP's are all too willing to give out prescriptions, and if the medication doesn't suit then it goes to waste. They felt that they shouldn't give out a month's supply of drugs until they find out after a

few days if the medicine is suited or not, they feel that there is a lot of money being wasted on unnecessary treatment and resources could be allocated elsewhere.

Sexual Orientation/Gay Community

In an ideal world, what would you expect true User Involvement to mean?

For the group in question in order for them to be truly involved it was felt that there was a need for more community partnership, involving people who are more familiar with the needs of this particular community. The people in question felt that there were a number of difficulties with the health services that they received. They felt that there was a problem with waiting lists in the NHS, especially in the Western Board area where there is a waiting list of up to two weeks at STD's clinics. This group felt that a helpline for people who suspected they had a STD should be available, with a trained member of staff manning the lines. Otherwise this group felt that medical problems of this nature would be left untreated due to having to wait too long and not having the courage to call again.

The members of this group also felt that there should be alternative therapies such as reflexology available on the NHS.

A questionnaire left at STD's clinics was suggested by one member of the group to be a good idea to access peoples views of the

services as they themselves feel that at present the structure of the services in Altnagelvin is very intimidating and unfriendly, leaving people feeling very uncomfortable.

What sorts of decisions about health services do you feel you should be involved in making? - Decisions about service planning, service delivery etc.

People in the gay community should be represented in Health and Personal Social Services committees and groups to enable them to have a say in how services are planned and delivered.

Community based groups should be involved at every level of the decision making process. It was suggested that groups should meet at least once a month to exchange views and opinions.

This group felt that if they had a choice then they would like to inform the health services that there should be different STD clinics for males and females, such as they do in the Royal Hospital in Belfast. The Royal hospital has separate entrances for both males and females which the people in question felt was a much better structure to the one in Altnagelvin hospital.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

Yes a user panel with the representatives of the 9 categories would be a useful and workable way of involving people in the gay community, as by doing this the gay community would not feel that there are been segregated. A user panel that includes all communities would enable the sharing of information to take place. For example what has worked well for one group may also work well for another. This group felt that it was very important to have a strong community influence when Health and Personal Social Services are planning and delivering health services.

Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - What are they?

This group felt that some members of their community might not have the skills or confidence that would be required to take part in user panel. They felt that training would be a good idea for users. Advocacy was felt to be another useful way to involve users, especially for people who live in rural areas and those who do not have the access or knowledge to be involved themselves. They felt that the NHS should provide Advocate services.

The people in question felt that the training of professionals was a very important issue, especially in training GPs when dealing with people of the gay community. One particular user had a very bad experience when visiting their GP. They felt that they needed to develop a more user-friendly approach.

“More people skills are required”.

Venues are another very important issue for this client group. Meetings and consultations should take place in the correct environment where people feel that they are safe. If a general community centre is to be used, then there should not be any stigmatisation, such as

“ This is a meeting for the gay community”

Anonymity is vital.

Jargon was also suggested to be a problem when users in the Gay community are being consulted. The use of language that is understandable was seen as a way forward.

“Use lay mans terms, use a language that everyone understands”.

The majority of this group felt that more could be done to involve the users and closer links should be developed. One person felt that there is often mistrust as people are at present being over consulted. Felt that user panels can become a meaningless exercise if views and opinions don't actual affect change in the services that they are receiving.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

People are sometimes unaware of how users can actually get involved in the planning and delivery of health services. This group feel that they would need more information on how to get involved. They also felt that gay people living in rural areas are of a particular disadvantage and often can feel isolated. It was suggested that information about health services and illnesses should be available in libraries, health centres and community centres, either in the form of leaflets or on notice boards. However they felt that information should not be given on a one off basis but must be given on an ongoing basis to ensure user involvement. Media campaigns was suggested to be a useful way of engaging a wider audience, and would be useful in getting information to people who live in rural areas as more than often there is poor community networks. However it was felt that media campaigns should be user friendly with relaxed tones, explaining what can and cannot be done and what services are available. One member of this group felt that health service professionals should put themselves forward as the spokesperson.

Giving people feedback from consultation was seen as a very important matter for this group. One member has been involved in a number of consultation processes but has never got any feedback.

“Not getting anything back just puts people off, it only leads to fewer and fewer people getting involved until eventually no will want to take part any more”.

True user involvement would mean that the users of services actually see that what they have said has impacted on the services that they receive.

Do you know of any initiatives/have you been involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these projects? What was poor about these projects?

The participant took part of an Alcohol and Drugs awareness programme (the participant was not sure of the name of the project), but no feedback was given. This participant felt that this was very bad practice.

Anything else?

One member of this group felt that Health and Personal Social Services providers should have to give annual reports on what is being done throughout the year and what changes has been made to services, especially in services that users have been consulted. Reports should be made available to the public.

Mentally Disabled

In an ideal world, what would you expect true User Involvement to mean?

More say in your own treatment was seen to be “true” user involvement for all the people in this group. A number of the users in this discussion suggested that they need to be consulted more, either to them or to their advocate at times when they are unable to speak for themselves due to their illness.

At present these users feel that treatment is done to them and not with them. An explanation for this by one member of the group was that they find some professionals are intimidated by them especially if they are able to articulate properly with them.

“If we can speak their language, so to speak.”

The majority of this group felt that they would have to be consulted at the very beginning,

“You have to use the user and not feel that they are a threat to you.”

The skills of the user must be recognised so that professionals will look at them as a resource and not as their enemy. Needs to be some form capacity building.

Some of the group felt that there needed to be a change of attitude of health care professionals. They felt that many health care professionals, particularly the psychiatrist are reluctant to give over power to the user.

It was suggested that in order to combat this it was essential to re-train health professionals, in particular those who are involved in the care of people with a mental disability.

It was mentioned that,

“Health care professionals would need to look at the human being first and the mental illness second.”

A number of people also felt that in order that everyone is involved the Health and Personal Social Services providers would need to provide training for the user so that they are better able to understand and contribute to their care in a meaningful way.

“The medical model has failed, we need something in between the top down-bottom up approach.”

What sorts of decisions about health services do you feel you should be involved in making? - Decisions about service planning, service delivery etc.

The respondents in this group all felt that they would like to have more say in their treatment, they would like to be involved more in their care plan development. They also would like to see a new mechanism being developed when people are been admitted to psychiatric wards in hospitals. To a large extent the people in this discussion felt that when people were already in a very vulnerable state, feeling afraid and isolated, they were often left in a room on their own before being assessed and admitted.

One member of the group felt that the best methods to deal with patients with a mental disability would be for a doctor, nurse, or health care professional to sit down with the client from the outset of treatment. This would involve the professional giving the patient an explanation on exactly what is happening and what their treatment will entail. They felt that the patients/users would need constant feedback eg if any changes are to be made in regards to their care.

Actually consenting to treatment was brought up as another area of concern for this group of users.

“Professionals need to listen to the patient when they are being treated, if a person feels that they don’t want a particular type of medication it should be their right to refuse it, many times this is not the case.”

Do you feel that a user panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

Individual specific user panels and user groups is the preferred model for the majority of this group. The majority of respondents felt that the needs of specific groups were too diverse to include everyone in the same user panel.

Are there any specific issues which would prevent users such as yourselves either being involved in a User Panel, or making their views known? - what are they?

Expense of attending meetings and getting involved on a user panel was considered a barrier for some of this group. These people felt that expenses are sometimes reimbursed but if this is not immediate then they are out the expense at the time, which just isn't feasible as most group members are surviving on already stretched budgets.

One member suggested that they be paid for attending meetings or sitting on user panels in the same way that professionals are paid to give their views and opinions.

"I have never been paid to attend a meeting or even been reimbursed, and I have attending a number of meetings."

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

It was felt by a number of people in this group that there was little research being carried out in the area of mental health and how to involve the service user.

They also felt that the existing research keeps bringing up the same issues time and time again. Therefore,

“ why isn't anything been done to address these issues.”

One member felt that even though there are some good practices out there they felt that health care professionals are letting good opportunities past by as they are not following the good practice that already exists. They felt that this was hindering the process of some mentally disabled people from getting well.

Do you know of any initiatives/ have you being involved in any projects in the past, which sought to involve users in decision making? What has worked well/was good about these projects? What was poor about these projects?

Italian model of mental health and the Scandinavian model of mental health. (see appendix-). The members of this group feel that Health

and Personal Social Services providers have to aspire to these models.

However one participant of this group felt that there is a wind of change coming. Their organisation educates people about their condition and discusses with them what works best for them; they feel that this would be a model that should be followed by all Health and Personal Social Services providers.

Another project that one member of this group was involved in was the Oasis project which involved shadowing a senior member of the Foyle Trust. It gave this member a real learning experience. They feel that it would be a good idea for Health and Personal Social Services to provide more opportunities for services users to shadow a senior member of trust. This enables a trust to be build up and helps users see the sort of restrictions that health service providers have to deal with on a day to day basis.

Anything else?

Some sort of refining system has to be put in place in the process of user involvement. In order to achieve objectives there needs to be a greater degree of flexibility.

Mentally Disabled – Session 2

In an ideal world, what would you expect true User Involvement to mean?

“To me it would mean that in clinical situations people should have more say in their treatment.”

This is what one participant felt when asked this question.

It was felt that there was a need to change policies and procedures as sometimes they felt that they understood how they were feeling better than any professional. The participant felt that there was an unwillingness of professionals to give over some control to patients, especially where a mental illness was concerned.

Bad attitudes of staff were also a problem.

“I was told to go home and pull myself together, what did I have to be depressed about”.

Re-training of staff was seen to be one way of dealing with this problem, with particular reference to patient care being addressed.

Involvement from the outset of their care was seen to be another way of ensuring user involvement.

“If you know what’s happening from the very beginning you feel you have better control, therefore you can find ways to deal with your illness”.

What sorts of decisions about health services do you feel you should be involved in making? – decisions about service planning, service delivery etc.

It was felt also that you should be able to choose what doctor should care for you, and health services should find ways to reduce doctor’s waiting lists. Fewer student doctors should be used on wards as it was found in this case to be very intimidating.

“You should have a say about the environment you are cared for in”.

People with all types of mental illness were grouped together in one hospital and this particular participant found this to be very unsettling, especially if someone had a more severe mental illness than they did.

The actually physical environment in one case was also deemed to be an area of concern. Non-smokers were grouped with smokers.

Do you feel that user panels would be useful and a workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

“Yes users panels are a good way of involving users, however there can sometimes be a reluctance for users to get involved because of professionals”.

“I feel that the best people to sit on these types of panels are those who have experienced mental health problems themselves”.

It was also felt that mentors and visitor groups should be set up for those in rural areas or those who could not represent themselves. It was suggested that this should be tested out first, as there may be an element of mistrust from mental health users.

Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - What are they?

This participant felt that training for the public/users to help them make decisions about their care should be provided by the Health service. Where and when the training took place was deemed to be irrelevant for this user as long as expenses would be covered.

What can Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

“Need to put structures in place so that people of ethnic minorities can have care in their old age, there would need to be interpreters to deal with language problems”.

This participant also felt that the Health and Personal Social Services should provide support and training for those who cared for users, whether it was people from an ethnic minority background or people with a mental illness.

Sexual Orientation/Transsexual

In an Ideal world, what would you expect true user involvement to mean?

The Transsexual Community representative felt that in order for the people in the Transsexual community to be involved in the Health services they receive they would need to be truly listened to and their opinions valued.

What sorts of decisions about health services do you feel you should be involved in making? - decisions about service planning, service delivery etc

It was felt that there needed to be a change in attitudes, especially of staff in Hospitals, Clinics etc. (the representative felt that staff in some cases had a very aggressive attitude towards transsexuals).

It was suggested that one way to change attitudes and change the culture of staff and management alike was to retrain staff. This would be so that there would be structures set in place and staff would be better informed and equipped to deal with any problems that arose when dealing with the Transsexual community.

“Staff must realise that there are mental as well as physical problems.”

It was felt that in a small number of cases there was already good practice in place to ensure that Transsexuals received efficient and effective health services and these should be shared across all board areas.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

After discussion it was revealed that another way to ensure Transsexual community involvement would be to have the “right” people on board when consultation takes place. Panels must be more open and have the right representation. It was suggested that a good

way to consult with the Transsexual Community was through their GPS as well as through “Press for Change”.

“If you want to reach the right people you must make sure that you involve the right people, make sure that transsexuals are involved and not gay groups”.

“Remember that Transsexuals are not a third sex”.

However it was recognised that this might not always be possible, as there may be prejudice from other members of the public.

Are there any specific issues which would prevent users such as yourself either being involved in a User Panel, or making their views known? - What are they?

Confidentiality was considered a major problem for Transsexuals and would seem to be one of the major barriers to “user Involvement”.

1 in every 4600 people in Northern Ireland is Transsexual but only a quarter of those would be willing to sit on any type of committee, either through lack of confidence or unwillingness to be identified due to fear of prejudice.

Medical records came up as another major issue, with regard to who has access to them, and who should be able to access them, the

participant felt that there needed to be a tightening of procedures here.

When meeting with the Transsexual community the representative present suggested that location of venue was not a problem and indicated a willingness to meet anywhere and not just at a place the community was familiar with. Felt that at times there could be abuses of finances.

Anything Else?

Community Services

The participant felt that the Health service providers are going to run into a lot of problems here. There is a lot of fear for the older transsexual community, again because of lack of understanding and bad attitudes of staff and residents alike. It was felt by this respondent that there was a need to put structures in place for the Transsexual community in areas such as old people's homes and Hospice care etc.

Employment of Transsexuals

As previously mentioned 1 in every 4600 people in Northern Ireland are Transsexual but not one member of the 9600 health service staff in the Western Board Area is Transsexual. This is also seen as a major barrier to user involvement. It was stated that there would be

more confidence and willingness for the Transsexual community to work with Health and Personal Social Services providers if a member or members of the Transsexual community were employed as members of staff.

Participant felt that there needed to be a fresh look at policies and procedures here.

Womans Groups

In an ideal world, what would you expect true User Involvement to mean?

For this user group, in an ideal world true user involvement would only take place if they knew exactly what services the Health and Personal Social Services providers offer, and what is available to them. They fear that unless they are truly informed about services then it would be very hard for them to get involved in the planning and delivery process.

This group suggested that information packs should be left at health clinics, community groups, leisure facilities, or given out by health visitors to inform the user of the services that are on offer. A free phone help line was thought to be another way to get information to the public on the health services the Health and Personal Social Services provide. This group felt that the service would need to be user friendly, especially for the elderly or ethnic minorities,” may be a

language barrier". They felt that the use of answering machines was not a good idea for certain groups. E/g the elderly, sometimes automated telephone lines can confuse and frustrate the user. A separate line for different communities was seen to be the way forward.

This group also aired their views on the availability of GP services, and about the waiting lists in hospital appointments and GPs. The majority of this group felt that they should have more access to doctors at the weekend, with a direct telephone line on emergencies.

For true user involvement to take place it was felt by this group that there should be better communication, and more partnership working between different groups. Community based health service was seen to be a better way to get users involved as you are bringing a service to the people especially if it is locally based.

Community workers/lay workers were seen to be a good way to ensure that people are aware of what services is available to them. People have more trust when they are familiar with the person rather than a stranger.

School nurses were also seen to be another way to help children access information about the health services, more informed about services and better links made.

What sorts of decisions about health services do you feel you should be involved in making? - decisions about service planning, service delivery etc

A few members of this group felt that they should have more of a choice when it came to accessing services, felt that waiting lists were too long at both hospitals and at GP surgeries. A few also felt that there should be a better system when seeking a second opinion in regards to a medical condition.

A number of this group felt that they should be involved in the allocation of resources and should have a say in how the money is actually spent.

One member of this group felt that users of services should be involved at the very beginning of developing a new service. If users were consulted they feel that they are empowered and it would take away any teething problems. Suggestions on how to be involved included the use of questionnaires, the use of Focus groups and the use of one to one interviews.

Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

This entire group felt that a user panel would be a workable way of involving the user. They felt that a general group, which included

elected representatives from all nine categories would be better than a specific group of users. They felt that everyone could feed into one another to form a chain of information.

It was felt that training might be needed to involve users who are not comfortable or aware of the procedures of a meeting. However they felt that there were quite a lot of the public who would make very good representation on user panels as they had a wealth of life experiences.

This group felt that there would need to be a change in attitudes of the professionals, and a change of organisational structure.

“Users would need to feel that their views are being taken on board and listened to”.

There is a lot of mistrust in this area in regards to the health service providers.

Local people were consulted in regards to service provision in their local Tyrone and County Hospital, but this group felt that their views and opinions didn't matter as they went ahead and close as what these people see as essential services. This group felt that the travelling to a hospital in Enniskillen was far too much, especially for young people and children. It was felt that these vulnerable groups may need more help than anyone else

Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - what are they?

More support is needed in order that users can be involved, especially the involvement of single mothers/fathers. There is also a need to provide facilities for single parents if one child has to be admitted to hospital. A number of this group felt the Health and Personal Social Services providers should provide a service whereby other children can be looked after particular in the case where there is no family support. It was felt by a number of members of this group that this was a very important issue, and would need to be addressed immediately. This group felt that by closing a very important service in this area people's lives are being put at risk. This group felt that in rural areas there is a need to have a rapid response ambulance, and they now feel there is a need to train members of the public in first aid, with a monitoring and supervised service also put in place.

It was felt that locally held meetings would be the best way to include this group in user panels, with only a few members, but a link with a general group of other users is important to get feedback. The time and location is also important when trying to reach a mix of the community. A number of this group felt that there was a need to give a least two weeks notice when attending meetings.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

The use of focus groups to consult with the user was seen by this group as one way that users could be involved in decision making. The use of user panels with elected representatives from all categories was seen to be another effective way of involving the user. Advocates should also be providing to help people who cannot speak or having the confidence to speak for themselves.

It was felt that there is a need for immediate feedback from any complaints made about the health services. However there was a mistrust of the health services by a number of this group who felt that if any complaints were made it might affect the future services that they receive. One member said that it was every person's right to complain.

Do you know of any initiatives/ have you being involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these projects? What was poor about these projects?

No other initiatives were mentioned.

Anything else?

Lack of resources would need to be addressed by the Health and Personal Social Services. Hospital still closed even though the public were consulted and against its closure. Haven't got proper feedback as to why the decision was made to close the hospital. People in this group feel that the consultation process can be a waste of time and money if their views do not affect change. Money could be better spent and needs targeted better.

Waiting lists need to be looked at.

GPs should be advocates for patients when it comes to hospital waiting lists

Needs need to be prioritised.

Users need more feedback as to what and why things and decisions are being made in health service planning and delivery. This group suggested that this could be done by way of newsletters, public meetings etc.

“There is a need to spell out to local communities on the ground what is done after they have been consulted”.

This group also felt that health professionals would need to be trained in people skills, not only on how best to involve the user, but how best to deal with them in an a friendly and approachable manner.

Sexual Orientation/Lesbian Community

In an ideal world what would you expect true user involvement to mean?

For this group of users true user involvement would mean that professionals would need to come down off their pedestals and deal with people at ground level.

What sorts of decisions about health services do you feel you should be involved in making? - Decisions about service planning, service delivery etc.

This group felt that they should have more say in how services are planned and delivered as they feel that people of the lesbian community are the best people to identify their needs.

One member of this group felt that they should be able to say what is services are available for them eg Health centres. They felt that Health Centres should be the centre for information and advice on sexually transmitted diseases, to try and take away some of the stigmatisation that is associated with sexual health clinics.

Another member of this group felt that section 75 of the Northern Ireland act is only touching the tip of the iceberg. There is a mistrust that user involvement has only come about because of political

motivation as they feel that people are still not getting the type of services that they would want.

The members of this discussion felt that the lesbian community is still been discriminated against in the type of health services that they receive. They feel that there should be a representative to get their voices heard.

Do you feel that a user panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

Yes. All members of this group felt that a user panel would work, as they felt that every member of society should have the opportunity to get their voice heard. They felt that all the 9 categories should be represented in this type of panel.

Are there any specific issues, which would prevent users such as yourself either being involved in a users panel, or making their views known? - What are they?

There is a lack of trust of the Health and Personal Social Services providers by the lesbian community in this discussion; they felt that there needed to a change in culture by the Health and Personal Social Services professionals from the top down

They also felt that professional need to talk in lay mans terms,

“Professional should talk in everyday language that everyone will understand”.

One member of this group discussion felt that the structures within the Health and Personal Social Services should be made more user friendly. They also felt that the image of the organisation would need to be more open,

“Less of the men in grey suits, so to speak”.

An open door policy was seen by all the members of this group to be a good system.

One member of this discussion also suggested that they would only become involved if a member of their own community represented them. They feel that sometimes health professionals see themselves to be on a different level than the everyday people on the ground. They felt that heads of boards should be more open and be more accountable about decisions that have been made.

The people questioned here felt that venues would be a big issue for them. They felt that they needed to feel safe wherever they were regardless of the circumstances.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

The members of this group felt that there was not enough information out there to let them know how they can become involved in health services decisions. They felt that different health centres should provide information and run media campaigns to get information across. Another suggestion was that the Health and Personal Social Services providers could set up a health outreach shop where information from all of the organisations can be put together and accessed easily. It was suggested that a touch screen computer screen was a good idea to access information quickly and effectively.

“If you know how the structures of the organisations work, then you would have more of an influence on the services if the information is at hand”.

Do you Know of any initiatives/have you being involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these projects? What was poor about these projects?

One member of this group was involved in the development of a lesbian helpline, however it folded up due to lack of resources and funding.

Another member of this group suggested that,

“Why should ordinary people on the group be aware of health initiatives if there is no information out there for them to access, why would they know if they have no experience in it, and what does that say about the health services”.

Anything else?

The participants of this focus group felt that the general public would need to be aware of the gay and lesbian community's needs. They felt that health services should fund community awareness programmes. These members felt that they needed community acceptance. It was felt that if people are more aware of their own needs and the needs of others it may keep suicide rates between the gay and lesbian community down.

Programmes in schools to make people more aware of theirs and others sexual orientation was also suggested as a way forward.

Although this group felt that there were more social acceptance of the gay/lesbian community now than before they still felt that there needed to be a lot more done to help change attitudes. Their community needs to feel that they have real input in decisions and not just dictated to. They also felt that there needs to be more done for the lesbian and gay communities in rural areas.

“This is where people often feel more isolated and suicide rates are greater”.

Another participant felt that their needs would only be listened to whenever it starts to pay,

“In order for health services to provide a service it needs to financially benefit them, therefore people are left out in rural areas as the health service need numbers”.

Men

In an Ideal world what would you expect true user involvement to mean?

The group in question felt that Health and Personal Social Services providers would need to come to them to have their opinions and views heard. They felt that they should be more open and honest,

“There should be no cover ups”

These participants of this discussion felt that Health and Personal Social Services providers should make adequate responses to complaints, adapt clear communication channels and have respect for each other’s experiences and expertise.

They felt that all Health and Personal Social Services staff should be properly trained, are able to speak in plain and easily understood language and use plain language in forms and policy documents.

What sorts of decisions about health services do you feel you should be involved in making? Decisions about service planning and delivery etc.

Strategy/policy/ complaint procedures in all areas of service planning and delivery.

Specific men's health programmes.

Do you feel that a user panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the Health and Personal Social Services?

There was a mixed reaction to this question; some didn't feel that it was a good idea others felt that it would be better than the status quo that exists. These members of the group felt that it would allow for more public representatives in the decision making process and that it would be a good consultative forum.

“It could be the grass roots that feed in from society at large”

Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - What are they?

Issues that the majority of this group felt that would prevent them being involved are that of mistrust of Health and Personal Social Services providers. They feel that there is too much tokenism, there is a power imbalance. Feel that consultation is only a talking shop and it isn't always worth the personal input given. There was also an issue of time and financial costs and commitment.

“Will being involved actually make a difference for the group of people that are being representative”?

The majority of this group indicated that thought needs to be given about time, length and frequencies of meetings.

“Would Health and Personal Social Services providers take the time to get to know/value the people that are involved”.

What can the Health and Personal Social Services do to make sure that users are more involved in decision making in the future?

Suggestions made were,

Create a key independent post for someone to collate user's feedback/complaints and front line staffs knowledge of users to evaluate and feed back into the system.

This group also felt that Health and Personal Social Services would need to publicise and explain what they are about, why they want to do it and how it will help services.

It was also felt that Health and Personal Social Services providers would need to communicate openly and honestly with users and that they do not penalise to those who complain or give constructive criticism of a service.

Do you know of any initiatives/have you being involved in any projects in the past, which sought to involve users in decision making? What worked well/ was good about these projects? What was poor about these projects?

Politics was given as an example where it was stated that you can complain about them but we chose them and as a result live the consequences of their actions.

Advocacy groups, in particular mental health groups were mentioned as a good example of users developing responses, parity from professionals in the health services.

The Retail industry was mentioned as good business example of how it responds to its users' concerns/needs/demands. It was suggested that you look at some business marketing models

It was said that there needs to be accountability and a genuine human face to any user involvement that aims to secure the support of users or their representatives.

A number of participants said a community development model could be used. The Voluntary Activity Units has a published document that could show possible ways forward.

Anything else?

There was ongoing debate as to why the Health and Personal Social Services wanted a user's panel and if it was not just another good idea by them to make them look like they were doing something constructive. A number of participants who had some experience of working with statutory bodies gave the viewpoint they felt it was an honest attempt to change things for the betterment of all. It was agreed that instead of knocking the service (mainly because of participants' past negative experiences) we should work together to understand the problems faced by Health and Personal Social Services and see if we can help them find solutions to problems/planning etc that affect us all.

Carers

Carer's national was consulted and information gained from them included.

It was recognised that planners of services need to involve users to make sure that they develop the services people really need and target those services most effectively.

Carer's involvement like users of services, need to be involved at all levels, from individual assessments and care planning to reviews of government policy on community care.

It was felt that carers need to know who to talk to, and what their rights are.

There are three key areas where carers feel professionals can help:

- By being honest with information, and honest about restrictions on them;
- Through demonstrating an open, empathic attitude which values the carer. Carers want to be able to communicate on an equal basis with someone who listens, and is committed to responding in some way to what they hear;
- Through working to develop mutual trust and respect.

Previous bad experiences of not being listened to or not being valued is very off putting and sometimes stops future involvement. This was considered an important issue for carers.

Another major problem is the use of jargon; it was felt that there was a need to address carers and individuals in a language that is understood by all.

Some carers defined consultation as

“Seeking my opinion and involvement in the decision-making process”.

“A two-way process with follow-up and feedback within a short timeframe”.

Guidelines and essential elements that Carers National feels necessary to involve carers include.

- Have a range of carers involved, not just one representative.
- Use wide spread advertising to encourage people to come forward.
- Think about transport arrangements, timing and venue for meeting and cover all costs.
- Equal status for all participants is essential.
- Create opportunities so that carers know the system, provide training if required.

- Consider what the carer can offer the professional.
- Feedback from consultation needs to be widely disseminated.
- Review and monitoring should be built in and clear lines of accountability.

DISCUSSION

The purpose of this study was to determine the views and opinions of both Health and Social Service providers, Community and Voluntary organisations and Health and Social Service users on how to involve users in the planning and delivery of services. It also aimed to examine experiences and look at ways in which users would like to be involved in order to shape and developed a set of guidelines for the Health and Personal Social Services on how best to involve users when planning and in the delivery of Health and Personal Social Services.

It is clear from the results that the majority of those questioned feel that it is very important to include and involve users in the planning and delivery of services, both in the Health and Personal Social Services and the Community and Voluntary sectors. The vast majority believed that in order to be responsive to users they need to and must be involved. Their involvement in turn would lead to a more focused, efficient and effective service being created.

Overall the study found commitment to the involvement of users in both the Statutory and Community and Voluntary sectors. It was

found that all of the Health and Personal Social Service providers who responded involved users in the planning and delivery of the health services they received alongside 92% of Community and Voluntary organisations. Commitment to public involvement has been outlined in organisations that have developed user involvement policies. Policies however would need to be developed in conjunction with Health and Personal Social Services providers and health service users. Setting policies to users needs are felt to aid in the development and delivery of better services. This study found that the Health and Personal Social Services providers questioned are quite willing to embrace their responsibility of involving the user.

A large number of organisations have developed a multi-agency approach to involving the user, this has brought a wide range of staff and users together, working in partnership with one another to discuss the planning and delivery of new services.

In comparing the results from both the Health and Personal Social Service Providers and the Community and Voluntary groups there is not at lot of variation of how each involve the users of their services.

User committees were the most popular method of consulting with users of services. The respondent groups however employed a wide variety of methods. These methods included, questionnaires, one to one interviews, user forums and focus group discussions.

All the organisations and individuals questioned agreed that there were no one best method to involve service users. Those questioned felt that for specific groups of users particular methods of engagement were best. One to one interviews were seen to be the best way to involve people with a learning disability by a number of the Health and Personal Social Services provider's who responded. This also reflected the views of some of the Community and Voluntary groups who answered questionnaires and took part in the Focus group discussions.

User panels were regarded to be a good way to involve younger people, people with a disability, people of the gay community, etc, but were not considered a good way to involve older people in the community. It is therefore recognised that when engaging and consulting with users the composition of the user group would need to be addressed and their particular requirements accessed so that their involvement is meaningful and maximum benefit is gained by their inclusion.

It was also recognised that there are a number of barriers to involving users both in the Health and Personal Social Services and the Community and Voluntary sectors. Lack of understanding, lack of resources, bureaucratic inflexibility, and apathy amongst users. Other perceived barriers were that of training and capacity building for the service user and the service provider. Accessibility to information, resources, locations and timescales were also seen as major barriers to including the user.

It is recommended that all areas of involvement would need to be addressed before users are consulted. These include using accessible language, looking at the formats of meetings, ensuring that users are supported when attending meetings. Trying to make sure that there is more than one representative for each client group.

Providing resources is also deemed essential to involve users in a meaningful way e.g. providing travel expenses, care support costs etc. There were a number of suggested ways to get information about health services across for particular clients groups in this study. For young people notice boards in schools could be used to provide information, alongside the use of attractive websites. Older people felt that information should be provided on a one to one basis or delivered free to their door. STD's clinics were a suggested means to gaining information on health services by the lesbian and gay communities.

It was found that users of mental health services do not identify with their needs in the same way as professionals and that they have different priorities (Hogman, G. 1993). Another important finding is that users of mental health services have low expectations, because they are so used to having services done to them and not with them. This is then said to lead to uncertainty for the user when asked what would be needed to improve services for them. Users need to be equipped with all the necessary information about the service. This may include an understanding of how the planning cycle works and

people's rights. This again suggests that service providers design the means of involvement around the specific user group and cater for their needs.

Some authorities in England pay users as consultants, and provide finances and facilitators for them to set up independent groups to represent users in planning. (Hogman, 1993). This was supported and recognised by a number of respondents in this study. The respondents feel that they are the experts and that they have a wealth of experience to offer which is all too often taken for granted. They therefore feel that they should be paid in the same way as outside consultants. They also feel that a lot of good work is being carried out by Community and Voluntary groups and that Health and Social Service providers need to recognise this and provide the funding to sustain these groups.

Others have developed policies in order that user representatives can participate fully in the planning process. These include, a policy on jargon, this co-insides with the organisational policies of the majority of the respondents in this study. Other areas of good practice for specific user groups can be identified in the literature overview.

Effective training and support is the foundation to providing high quality services and this has been recognised by the majority of those questioned. Users may feel that they do not have the necessary skills or the confidence to be involved in health service decisions. By providing training to service users and service providers services will

be enhanced. Any future training courses to ensure high quality services should strictly follow guidelines for the specific client group. It is recognised from the research that users of specific services, such as mentally disabled, physically disabled, are best able to provide awareness training to both users and providers

There is a lot of dissatisfaction with the extent that Health and Personal Social Services providers involve users in the planning and in the delivery of health services. Responses varied, only 21% were happy with the way users were involved, 46% were unhappy and 29% were unsure of the extent of users involvement. 4% didn't responded to this questioned.

It was felt that current planning is very much based on the professional knows best mentality, and they feel that not enough is being done to secure and use the views of the user.

Due to these results it is recommended that Health and Personal Social Services providers map out the extent that users are involved in the planning and delivery of health and personal social services provided

A large number of respondents were also unsure that the views of users actually make a difference and influence the services that they receive. One of the main reasons for these results was lack of information. User felt that they were not well enough informed to know if users views actually influence decisions and if their views

have been taken on board. It was also suggested that it often takes to long a period from the time a user is consulted until changes are implemented on the ground. It is therefore felt that Health and Personal Social Services providers would need to set specific timescales to provide feedback to users after they have been consulted.

Therefore there is a need for a clear framework to be developed to make users aware of how they can be involved in the planning and delivery of health services and how user involvement influences the health services that they receive. Giving feedback to users on all occasions where users have been involved is very important in order to ensure ongoing user involvement to aid the development of a continuous relationship between users and Health and Personal Social Services providers. Giving feedback ensures that Health and Personal Social Services are not just paying lip service.

Evaluation of services was also considered to be very important to the Health and Personal Social Services and Community and Voluntary groups questioned. Evaluation on the effectiveness of involving the user with the responding audience was carried out in a number of ways such as reduction in complaints, feedback from questionnaires, focus groups etc. It is suggested that alongside the service providers own evaluative structures it would be good practice to have outside monitoring agencies evaluate services in order to ensure that targets and standards are being met to involve the user.

The importance of involving the user in the planning and delivery of health services is said to benefit the provider by a number of the Health and Personal Social Services respondents. Users were seen as the experts, therefore by including them in the decision making process individual needs can be addressed and shortcomings in the service can be dealt with in a more effective way. Health service providers can benefit from listening to the views and experiences of service users; this can include both positive as well as negative feedback. Users can provide insight into gaps in service provision that professionals may overlook.

It is recommended that a framework is developed that can be sustained locally and feedback to all groups to display the benefits of involving users, together with nationally co-ordination to make the most of useful links.

The ways forward for those Health and Personal Social Services providers that were questioned ranged from the development and implementation of policy to a continuous relationship with other organisations, such as a multi-agency approach and a community development approach.

Commitment from organisations at a strategy level was identified as being a good way to include service users and keep them involved. Openness, transparency and commitment by health service providers were seen to be the best way to ensure ongoing user involvement by a number of Community and Voluntary groups questioned. It was

said that there needed to be a change in the culture of health service providers, alongside providing funds to sustain user groups for the future, providing the space, the expenses, and completing regular evaluation of the work and services that are taking place. Partnership working between statutory and voluntary bodies should be encouraged.

Some of the respondents in this study have been involved with a number of user groups within the Health and Personal Social Services and because of this there is a lot of scepticism of what the project will achieve. It was mentioned that the concept of user involvement has been disseminated over the past 4 years but the users on the ground are not seeing any direct change in services. Some respondents in this study while acknowledging that there is a lot of good work within the Health and Personal Social Services organisations and there is genuine attempts to involve the user they still feel that existing structures are not working as they have not created change. It was suggested that health professionals fit into community and voluntary structures that are known to work.

Concrete structures would need to be developed in the area of direct working so that change can be seen on the ground and not merely through consultation.

A lot of the issues that arose during feedback from questionnaires and Focus group discussions were actual service issues, issues continually arose in the area of accessing services. A substantial

number of respondents felt that waiting lists were too long at both hospitals and at GP's surgeries. Health and Personal Social Services providers would need to address these issues and strive to find ways to solve these problems.

There was a problem with the closure of a particular hospital even though users were consulted on the matter. A lot of mistrust of Health and Personal Social Services providers has developed as a result. What happens to users' views must be made clear to users. It is very important to respond to issues identified by the user even if the response is not what they want to hear. Users have to understand that consultation does not always mean action.

Respondents also felt that when authorities close a hospital they should provide support networks, such as the opportunity for members of the public to train in first aid. It was also felt that family support needs to be provided if patients or carers have other dependants at home if they require a stay in hospital that is too far away to travel.

Other service issues included:

- The provision of alternative therapies by Health and Personal Social Services providers.
- Personal care in nursing homes should be provided free.
- A new direct telephone line in doctor surgeries alongside more access to surgeries at the weekend.

- People of different religious beliefs and different ethnic minorities feel that they need to be able to choose the gender of the doctors.
- Single sex STD's clinics to improve confidential access. I.e. different entrances for males and females.

The views and opinions of users are important, and the benefits are numerous. The benefits to involving the user in the planning and in the delivery of Health and Personal Social Services include a more effective and cost effective health service, less abuse and more genuine usage of the health services if users have been involved in decisions. Users are better informed about existing provisions if they are included; therefore services are targeted more effectively to users needs.

CONCLUSION

Although this report has highlighted gaps in research in specific categories within section 75 of the Northern Ireland Act it should be recorded that a lot of good work is taking place to ensure that users are involved in the planning and delivery of Health and Personal Social Services. The challenge for all involved in the provision of services is to make sure that best practice identified as part of this study is built upon and guidelines implemented. From this study and through reviewing literature a set of guidelines have been developed for the engagement of users in the planning and delivery of Health and Personal Social Services. Providers need to appreciate and

understand the value of implementing the guidelines for both users and themselves.

REFERENCES

Deepa Mann-Kler (1997): An action report into Families, Racism and Exclusion in Northern Ireland.

Department of Health, Social Services and Public Safety (2000) Investing for Health. Belfast:HMSO.

Department of Health, Social Services and Public Safety (2000). Building the way forward in Primary Care. Belfast; HMSO

Hogan, G (1993) Building Bridges between people who use and people who provide services. www.elsc.org.uk/users_andcarers/bridges/bridcon.html.

Involving Users: Improving the Delivery of Healthcare (1999). A report from the National Consumer Council Consumer Congress and Service first unit in the Cabinet Office.

Irish Travellers, (2000) "Traveller's Health. www.paveepoint.ie

Kernohan, W.G. (2000). Methods of User Involvement in Children's Services Planning. Armagh: Southern Area Children and Young People's Committee.

Millar, B. (2000) Right on Target. Health Service Journal. 30 November: 16-17.

Obeid, A (2000) Perceptions of user participation in health care. JCN, 14 (4).

Strategic Health Authority area (2000) The Peninsula <http://www.Cornall.nhs.uk/cornwallNHS/asps/index.htm>

Wale, D. (1993) Building Bridges between people who use and people who provide services [www.elsc.org.uk/users and carers/bridges/bridcon.html](http://www.elsc.org.uk/users_and_carers/bridges/bridcon.html).

Project Details

The project is designed to gather views and opinions from HPSS Providers, Users of HPSS services, and Community and Voluntary Organisations, on the involvement of Users in Health and Social Services

Confidentiality Agreement

You will not be required to supply your name on any of the documents. Information will not be disclosed to any person or organisation that is not involved in the study. All information will be kept securely and anonymity is ensured. Filling in the following questionnaire is taken as your agreement to participate in the study.

Date: _____

Position / Job Title (optional)_____

APPENDIX 1

Questionnaire for Health and Personal Social Services.

Please complete all Questions as fully as possible.

Please complete questionnaire by ticking only one of the boxes provided.

List any reasons or general comments in the space provided below each question.

Q 1: Do you involve Users in the Planning/ Delivering services you provide?

YES **NO** **DON'T KNOW**

Please give details.

Q 2: Do you feel that it is important that Health Service Providers involve Service Users in Planning/ Delivering the Health Services they receive?

YES **NO** **DON'T KNOW**

Please give a reason for your answer.

Q 3: Are you satisfied with the extent that you involve Users in the Planning/Delivering of services?

YES **NO** **DON'T KNOW**

Please give a reason for your answer (If No please outline what else you would want to do to improve on this).

Q 5: What do you feel is the best way to involve Users in Planning/Delivering the Health Services they receive?

Give Comment.

Q 6: What do you see the benefits/ if any, to be of involving Users in decisions about the Health Services they receive?

Give Comment.

Q 7: What do you see the barriers / if any, to achieving and obtaining User involvement in Health Services decisions?

Give Comment.

Q 8: What do you feel is the best way for Health Service Providers to ensure ongoing User involvement?

Give Comment.

Q 9: Do you feel that involving the User enhances your services?

Give Comment.

Q 10: How do you evaluate the effectiveness of User involvement?

Give Comment.

Q 11: Please tell me of any User Involvement Projects that you are aware in your organisation, please specify and list any contact details below)

Give details.

Q 12: If you have anything else to add to this questionnaire on User involvement please state below and continue on a separate sheet if needed.

Give Comment.

Project Details

The project is designed to gather views and opinions from HPSS Providers, Users of HPSS services, and Community and Voluntary Organisations, on the involvement of Users in Health and Social Services

Confidentiality Agreement

You will not be required to supply your name on any of the documents. Information will not be disclosed to any person or organisation that is not involved in the study. All information will be kept securely and anonymity is ensured. Filling in the following questionnaire is taken as your agreement to participate in the study.

Date: _____

Position / Job Title (optional)_____

APPENDIX 2

Questionnaire for Community and Voluntary Organisations and Individuals.

Please complete the Questionnaire as fully as possible.

Interested Individual members may find it useful to skip the first Six Questions of the questionnaire, and begin to answer questions starting at page

Please Tick whether group membership will include, Persons of Different: (You may tick more than one Box).

AND

- | | |
|---|---|
| <input type="checkbox"/> Religious Beliefs | <input type="checkbox"/> Men |
| <input type="checkbox"/> Political Opinion | <input type="checkbox"/> Woman |
| <input type="checkbox"/> Racial/ Ethnic Group | <input type="checkbox"/> Persons with a Disability |
| <input type="checkbox"/> Age | <input type="checkbox"/> Persons without a Disability |
| <input type="checkbox"/> Martial Status | <input type="checkbox"/> Persons with Dependants |

**Sexual Orientation
Dependants**

Persons without

Please complete questionnaire by ticking only one of the boxes provided.

List reasons and any general comments in the space provided below each question.

Q 1: What service does your organisation provide?

Please give details below.

Q 2: Do you involve Users in Planning/ Delivering the services you provide?

YES **NO** **DON'T KNOW**

Please give details.

Q 3: How does your organisation involve the User?

Please give details.

Q 4: How much influence do the views of Users have on the Planning/Delivering, services you provide?

Give Comment.

Q 5: How do you evaluate the effectiveness of User involvement?

Give details.

Q 6: Please let me know of any User Involvement Projects that you are aware of in your organisation. Please specify and list contact details below.

Give Comment.

Q 7: Do you feel it is important that Health Service Providers involve Service Users when Planning/Delivering the Health Services they receive?

YES **NO** **DON'T KNOW**

Please give a reason for your answer.

Q 8: Are you satisfied with the extent that Health Service Providers involve Users in Planning/Delivering services?

YES **NO** **DON'T KNOW**

Please give a reason for your answer.

Q 9: Are you satisfied that the views of Users influence the services they receive from Health Services Providers?

YES **NO** **DON'T KNOW**

Please give a reason for your answer.

Q 10: What do you feel would be the best way to involve Users in Planning/Delivering the Health Services they receive?

Give Comment.

Q 11: What do you see the benefits/ if any, to be of involving Users in decisions about the Health Services they receive?

Give Comment.

Q 12: What do you see the barriers / if any, to obtaining User involvement in Health Services decisions?

Give Comment.

Q 13: What do you feel would be the best way for Health Service Providers to ensure ongoing User involvement?

Give Comment.

APPENDIX 3

GPR PROJECT FOCUS GROUPS

Date__ October 2002_____ Venue Derry_____

Steering Group Member_____

Participants Present _____

1.	In an ideal world, what would you expect true User Involvement to mean?
2.	What sorts of decisions about health services do you feel you should be involved in making? - decisions about service planning, service delivery etc

3.	Do you feel that a users panel would be a useful and workable way of involving representatives from the 9 categories in decision making in the HPSS?

4.	<p>Are there any specific issues which would prevent users such as yourself either being involved in a Users Panel, or making their views known? - what are they? (Test views about venues, times, chairmanship, papers in advance, expenses, length of meetings, number of people present, people from all categories present or just one category, feedback mechanisms, training of panel members/capacity building, expectation to link back to community members etc).</p>

5.	What can the HPSS do to make sure that users are more involved in decision making in the future?

6.	Do you know of any initiatives/ have you being involved in any projects in the past, which sought to involve users in decision making? What worked well/was good about these projects? What was poor about these projects?

7.	Anything else?
	I

Signed: _____ Date:- _____

APPENDIX 4

Our Ref: GPR 1

9 July 2002

To: Chief Executives, Trusts, Boards, Agencies
Chief Officers, HSS Councils

Dear Sir/Madam

RE: GOOD PRACTICE REVIEW – USER INVOLVEMENT

As you are aware, in taking forward the Equality duties under Section 75, NI Act 1998 the HPSS family are working in a collaborative manner. An aspect of this agenda is Good Practice Reviews (GPR), one of which has been allocated to each Board area.

The GPR, which we in the Western Board Area are taking forward, is on User Involvement. We are using a number of techniques to establish people's views and opinions on how to achieve user involvement, and on effective involvement mechanisms. One strand of this work relates to how user involvement has been tackled within the HPSS.

In order to collate information on this area, we have developed a questionnaire for completion. I am enclosing a copy with this letter. I would be very grateful if you could arrange for this to be completed, and returned to me by **16th August 2002**.

My contact details are:

Fiona McMullan

Project Support Officer

Lime Villa, Gransha Park

Clooney Road

Londonderry

BT47 6WJ

Phone no. 02871860616(ext.2189)

Fax no. 028 71 860468

Minicom: 028 71 860086

Email: fmcmullan@westcare.n-i.nhs.uk

You will see that the latter part of the questionnaire asks for some details on any specific projects, which have been taken forward by your organisation and associated, contact details. This is because we would intend to carry out short follow up telephone interviews with staff involved in projects of particular interest.

I am sure that you will want to contribute to this important piece of work, which will then be disseminated across the Province.

I look forward to hearing from you.

With many thanks.

Yours sincerely

Fiona McMullan
PROJECT SUPPORT OFFICER

Enc

frb/smc/109

APPENDIX 5

Our Ref: GPR 1

9 July 2002

Dear Sir/Madam

RE: USER INVOLVEMENT PROJECT

You will recall that I wrote to you recently to find out whether you would like to take part in a Project which I am working on. As you know the Western Equality and Human Rights Forum have employed me as Project Support Officer to carry out a Good Practice Review on User Involvement. I would like to thank you for responding to my last letter.

As you know, I indicated that the Project would involve both questionnaires and Focus group discussions, in order to understand everyone's views on User Involvement. I am very grateful that you expressed an interest in being involved, and I am enclosing a copy of the questionnaire with this letter. It would be very helpful if you could complete and return this questionnaire by **16th August 2002**

My contact details are:

Fiona McMullan
Project Support Officer
Lime Villa, Gransha Park
Clooney Road
Londonderry
BT47 6WJ
Phone no. 02871860616(ext.2189)
Fax no. 028 71 860468
Minicom: 028 71 860086
Email: fmcmullan@westcare.n-i.nhs.uk

Your contribution to this project is of paramount importance. Your views and opinions on user involvement will help to shape how User Involvement is taken forward in the future within health and social services.

If you know of any other groups or individuals who would like to be involved in the project, I would be grateful if you could let me know as soon as possible. Alternatively, please feel free to photocopy the questionnaire for completion by anyone else who has an interest in this work.

Please do not hesitate to contact me if you have any queries.

I look forward to hearing from you.

Yours sincerely

Fiona McMullan
PROJECT SUPPORT OFFICER

Enc

frb/smc/110