



Senses

Plan

Involve

Nurture



**Research into Joint Involvement
of People with Sensory Loss
and from the Deaf Community**

Funded by the Scottish Community Action Research Fund

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1 Section 1 - Introduction

1.1 Background

Fife Sensory Impairment Centre (FSIC) was established in 2000. It houses a number of services for people with sensory loss including Fife Council's Deaf Communication Service, Fife Society for the Blind, NHS Fife, RNIB Scotland and Sense Scotland. For the first time, these services are under the same roof. It brings opportunities for service providers and service users to work together to ensure services are responsive and meet the needs of people with sensory loss in Fife

While FSIC brings these agencies together under one roof, we still need to find mechanisms to involve and consult people with sensory loss and the Deaf Community about the development of services in Fife.

Obtaining funding from the Scottish Community Action Research Fund (SCARF) to carry out this research provided a positive opportunity for us to take this forward and because of the nature of the fund, it allowed us to do this in partnership with all the communities of interest. Without funding from SCARF we would have been unable to progress the idea of joint involvement and more importantly, we would not have been able to carry out research in a participative way.

1.2 The Aim of the Research

The FSIC research was set-up in June 2003 to look at ways of developing joint consultation with the various agencies and people with sensory loss to improve provision of services. The aim of the research was therefore:

“To develop a mechanism or mechanisms for jointly involving service users in the development of the Fife Sensory Impairment Centre”

1.3 The Objectives of the Research

The objectives of the FSIC research were:

- to develop the research skills of a group of local people with sensory loss, professionals and service providers;

- to seek the views of various agencies and people with sensory loss;
- to examine areas of good practice;
- to pilot innovative methods of joint consultation;
- to consider the findings and produce a report on good practice guidelines and tools for joint consultation;
- to disseminate the findings.

1.4 Involving People

When ideas like ‘involvement’ are used, we need to be aware of what they mean to us as it can mean different things to different people. At the start of our research, we spent some time thinking about the meaning of involvement and how we wanted to explore it in our research.

The words ‘involvement’, ‘participation’, and ‘consultation’ are often used interchangeably but there are different conceptual models. For example, Arnstein’s (1969) ladder of participation is one of the most commonly used and identifies eight levels or rungs of participation to show that it can mean very different things ranging from non-participation to citizen control and power.

8. Citizen Control	
7. Delegated power	Degrees of citizen power
6. Partnership	
5. Placation	
4. Consultation	Degrees of tokenism
3. Informing	
2. Therapy	Non participation
1. Manipulation	

Being clear about why, who and how involvement will take place are important. If defined too narrowly, or seen only as a repertoire of methods rather than a range of relationships, existing practice is devalued. Ridley & Jones, (2002) in looking at the literature on involving users and the public concluded that it could be looked at in terms of:

- The direct involvement of individuals and carers
- User and public involvement in service quality
- Involvement in policy and planning
- Involving people through community development

It is helpful to distinguish between involving people as individuals and as groups of people as users, carers, citizens etc. Also, there are 'reactive' and 'proactive' approaches. Involvement is multi-dimensional – levels of involvement vary from information sharing and consultation to user participation and direct control. In doing this research, we found it particularly helpful to distinguish between communication, consultation, and partnership and to be aware that there can be a world of difference between consulting people about services and involving people in real partnership to develop services that really meet people's needs.

1.5 Messages from Other Literature

In considering how to involve people with sensory loss and from the Deaf Community in this research, it was discovered that most of the available literature involved only one sensory loss and none included Deaf people.

A distinction is made in the literature between "reactive" and "pro-active" approaches to involvement which not only affect the purpose but the way involvement activities are carried out. The research recognised that involvement is a multi dimensional concept, for example, levels of involvement from merely sharing information through to user participation and direct user control all need to be considered.

Additionally, a telephone interview was conducted with a Researcher from Living Options in Devon together with a review of their published literature. This project established a monthly consultation group of people having a sensory impairment and including individuals having additional cognitive and physical disabilities.

This project provided useful data for the research group, most importantly a conclusion that joint user consultation could work. However this small group took over a year to establish and has had considerable specialist resource implications. Most importantly, these included involvement of a BSL Interpreter at all stages of planning and execution to advise on effective communication. The research team acknowledged that this was important but noted it need not be at the exclusion of including BSL Users.

2 Section 2 - How We Did It – Methods

2.1 Steering Group and Community Researchers

Originally it was planned to have a steering group to direct the research and a team of community researchers carrying out the research who would be people from the different communities of interest. However, during the course of this research, the steering group's role has changed resulting in the role of the community researcher being combined with those of the steering group members. This has come about due to the difficulties experienced in involving members with a sensory loss.

2.2 Research Mentor

The role of the SCARF research mentor was to assist with the development of the research by providing training and support to the community researchers as required. As a participatory action research process, this has involved everyone learning about research as it developed. Most of this learning and training has been informal while there has been specific training on facilitating and recording focus groups and interviews and analysing information. The research mentor's role also grew to involve facilitating the team's meetings. This was a reflection on the group underestimating the complexity of the task involved.

2.3 Administrative Support Worker

The research required administrative support to record meetings, book BSL Interpreters, meeting rooms and to provide all paperwork in accessible formats for people with sight loss. Midway through, it was agreed to employ an additional member on to the research team to provide these services and she greatly improved communication and efficiency.

2.4 FSIC Research Team

The FSIC research team has evolved through constant changes in staff within agencies and an unsettling period where there was a change in research mentor. As a consequence of this, service users felt the lack of consistency of members within the group resulted in information having to be repeated and the aim and objectives of the research not always

being clear to everyone. This resulted in the process taking longer than it might otherwise have.

This was a particularly difficult time for the BSL Users and this was addressed by having additional meetings with the research mentor and BSL Users to clarify issues arising from the research team's meetings.

The representation on the FSIC research team was as follows:

- 4 x people with sensory loss and from the Deaf Community
- 1 x professional from Fife Council Social Work Services
- 4 x professionals representing agencies that support people with sensory loss and from the Deaf Community and people with sensory loss and multiple disabilities
- 1 x research mentor
- 1 x administrative support worker.

2.5 Training

The research team met monthly and developed their knowledge of specific requirements of people with sensory loss as the research progressed. During these sessions several lessons were learnt by professionals/service providers and service users that ensured everyone was involved in the preparatory work required for the focus groups, individual interviews and pilot consultations.

This varied from the time taken to ensure the venue had a working loop system for hearing aid users, providing communication support for BSL Users, using graphics in publicity material and providing information in accessible formats for people with sight loss. Additionally it was acknowledged that the need for an administrative support worker to provide all the paperwork and communication support was required to ensure all the team's needs were met.

There was one specific training day delivered by the research mentor to develop the team's skills on facilitating and scribing at focus groups and one-to-one interviews. This included role-play followed by information and advice on how to make the sessions comfortable and inclusive. An experienced focus group facilitator provided the training alongside the research mentor.

Sensory awareness training and sighted guide training was not included in the training programme. With hindsight the research team felt that this was important for everyone taking part in joint consultation. For example, this would address the issues of people with sight loss speaking while BSL Users were signing and how this can be overcome.

2.6 Focus Groups and Interviews

Focus groups and one-to-one interviews were used to explore the views of the various communities of interest. The research team planned for 4 focus groups of 6-8 participants. At this time it was agreed to consult people as part of their individual target community. They were therefore invited to join specific focus groups, for example a group of people with sight loss. They were therefore not consulted jointly at this stage.

The focus groups and one-to-one interviews were drawn from the register of blind and partially sighted people that is kept by Fife Society for the Blind, the Deaf Club and Hard of Hearing Group. The research recognised that while people with sight loss can be contacted directly through Fife Society for the Blind's register, people who are Deaf or hard of hearing can only be contacted through existing clubs or the Deaf Communications limited database. A breakdown of the numbers invited and attending these focus groups and interviews is attached at Appendix 1.

The work involved in bringing these target communities together should not be under-estimated. It is time consuming and labour intensive and we did not manage to cover all the groups equally as we had planned.

The focus groups and one-to-one interviews were held to find out the target communities':

- understanding of the term "user involvement or participation",
- experiences of user involvement to date,
- views about what is good involvement and what should be avoided,
- perception of the barriers to involvement generally and joint involvement particularly and,
- ideas about how these barriers can be overcome.

A facilitator who was a service user and a minute-taker from one of the professional agencies conducted all focus groups and one-to-one

interviews. The minute-taker provided a record of the meetings that was also recorded on tape with the permission of participants. All facilitators and minute-takers were representatives of the FSIC research.

2.7 Pilot Consultations

Once the findings had been analysed from the focus groups and one-to-one interviews, two pilot consultations were taken forward to test out in practice what we had learned.

It was agreed to have an informal pilot consultation and a formal pilot consultation. The former focused on a physical activity session using exercise bikes at a local leisure centre followed by a consultation about the accessibility of the leisure centre. The latter focused on a current NHS public consultation. Details of both these pilots have been recorded in Section 4 of this report.

2.8 Conclusions

With hindsight an induction programme would have assisted members of the research team to understand the difficulties of involving people with sensory loss and from the Deaf Community. The research agreed that this would include:

- Clearly defining the aims and objectives of the project to anyone participating in the consultation;
- A clear definition of the roles and responsibilities of all members;
- Sensory awareness and sighted guide training for all members.

When applying for funding for projects that involve people with sensory loss and from the Deaf Community, our project demonstrates the need for:

- Electing an Independent Facilitator;
- Employing a research mentor;
- Employing an Administrative Support Worker;
- The practical issues outlined in Section 5 of this report.

3 Section 3 - Findings

3.1 People's Experiences of Involvement and What it Meant.

"Never been involved, would like to be asked by service providers, or to be taken out and asked in a practical situation or environment". (blind and partially sighted focus group)

**"Can't fill in forms, prefer a phone call or personal interviews."
(blind and partially sighted focus group)**

"Reported medical services after long waits, no notes ready and 13 month wait for appointments. Rapped knuckles and felt wasn't involved with own health until letter of complaint sent". (individual interview with person with sight loss)

"Its not just audiology. My downfall was that I just wouldn't admit I had a hearing problem and I missed a lot. The Hard of Hearing Group gave me the confidence to say I am hard of hearing, look at me when you speak." (hard of hearing focus group)

"Involvement means attending meetings; listening, learning, sharing ideas and getting information back in return. Sharing is important in creating an ethos of involvement." (hard of hearing group)

"Not sure what many words mean unless they can be interpreted pictorially and even then the wrong meaning can be conveyed". (Deaf Club focus group)

"Hearing people have to recognise and accept the different culture of the Deaf". (Deaf Club focus group)

"Not being isolated". (individual interview at Forward Centre)

"More training to identify needs and enable support specific to need. Availability of accessible information regarding support (e.g. signing, one to one). Discussion with those in the know regarding communication support and techniques of approach. Availability of Interpreters." (member of staff at Forward Centre)

As reflected in the quotations above, there were varying patterns of involvement that contributed to more meaningful consultation for the various groups. People with sight loss strongly emphasised their wish to have more practical and one-to-one involvement while people with hearing loss and from the Deaf Community felt more confident in a group environment.

This difference of views may not be entirely representative of the views of all people with sensory loss but as a result of involving people who were already part of an established hard of hearing group organised by Deaf Communication Services and an established Deaf Club for BSL Users. In contrast, people with sight loss were randomly selected from the register of blind and partially sighted people held by Fife Society for the Blind.

The research had initially planned to use publicity material that could be distributed to the audiology clinic and people on the Deaf Communications Service's database as well as those who are on the register of blind and partially sighted people. For various reasons, including misunderstandings in communication with the agencies within FSIC, it did not prove practicable to do this. The research found this had an overall effect on the promotion of the proposed research.

3.2 Joint Consultation and Involvement

When specifically asked about joint consultation and involvement and what would support this, the various groups responded positively.

"It would be informative if the management structure and service managers were identified. In the case of FSIC, information regarding the agencies offering services within the centre, contacts and a description of the services provided would be helpful."
(member of staff at Forward Centre)

"Can't see why they can't work together. Can't imagine anything that would stop it – a problem shared is a problem halved. Can only benefit working together." (individual interview at Forward Centre)

"There might be a problem as Interpreters are thin on the ground. It would depend on how often meetings were held and where."
(Deaf Club focus group)

“Lack of information becomes an obstacle. Decisions and requests cannot be implemented because individuals and groups don’t know the proper route to take. Recommend that heads of organisations form a steering group that communicates information to the service users/groups. This group would have the authority to discuss and recommend or not recommend the implementation of suggestions and requests.” (hard of hearing focus group about FSIC)

“There would be practical problems with communication; could write things down. What would happen with deaf/blind? Would need carers and personal assistants to explain what was going on, what is proposed etc. If this isn’t done people in the group could feel isolated and left out. Must understand each other’s problems so mustn’t “fly off the handle”. Have to find out what the “pitfalls” are in order for it to work.” (individual interview with person with sight loss/stroke)

“They are going to have to want to do it, if they are not interested they will not come.” (blind and partially sighted focus group)

Analysis of these opinions suggest that there is a positive interest in developing joint involvement and consultation but because this is outside people’s experience there are fears about how it will work in practice. A need was therefore identified for partners within FSIC to look at how they might bring together an information pack. This would assist service providers and users to understand what is available from the Centre as a whole.

While the aim of the research, to explore joint consultation, took for granted that people would want joint consultation, the research findings confirmed this assumption. Additionally the research concluded the establishment of a joint service user and providers management group for the Centre would be a positive way forward. This would assist in the development of all the services within the Centre.

It was also agreed that this shared responsibility would have a positive effect on external agencies using the services and may encourage others to promote a similar service within their organisations.

3.3 What Works Well?

The following quotations show the different ideas participants had about what supports good involvement and consultation and some of the issues relevant to planning a successful joint consultation.

“More thought needs to be given to communication” (blind and partially sighted focus group)

“There could be a forum including individual representatives from differing groups” (hard of hearing focus group)

“There could be confusion with the interpretation of words, graphics and pictures. Illustrating the text needs to be kept simple without crowding. Simple words should be used” (Deaf Club focus group)

“Being in a relaxed atmosphere.” (individual interview at Forward Centre)

“Good organisation in the first place. Identifying possible problem areas e.g. transport, venue, lighting, possible loop system. The time involved; would it be better to have one meeting or two shorter meetings”. (member of staff at Forward Centre)

Participants’ responses also suggested issues relating to:

- Timing of an event;
- Consultation must have a point;
- Good organisation when planning the event;
- Users wanted to feel they were being listened to: actions talk louder than words;
- Having a contact point: co-ordinate ideas and suggestions, somewhere to go with ideas;
- Awareness training: needs of everyone involved in consultation;
- Power of a collective voice;
- Impartial facilitator.

These points were taken alongside those noted from the focus groups and individual interviews as ways to overcome the barriers to joint consultation and meaningful involvement. These included:

- Communication: having a better understanding of other people's communication needs;
- More widespread basic BSL training for everyday conversations with BSL Users;
- Accepting other people's difficulties: things will take longer;
- Provide transport;
- Go to people, not expect them to come to you;
- Funding;
- Availability of working loop system;
- Training and awareness;
- Having a social element to consultation events.

All of these issues were taken on board when planning the pilot consultations. A draft checklist for planning consultations was drawn up and tested through the pilots. See Appendix 2.

3.4 Reflections on the Findings

The research identified that there is a register for blind and partially sighted people but not one for people with hearing loss and from the Deaf Community. The former provides a means for Fife Society for the Blind and RNIB Scotland to contact people with sight loss. The latter is reliant on people with hearing loss and from the Deaf Community contacting Deaf Communications Service for assistance and agreeing to be included on their database. The research demonstrated that this restricts the methods that can be used to contact and involve people with sensory loss and from the Deaf Community and relies heavily on the availability of human resource time within FSIC agencies.

Equally, the research acknowledged that professional agencies frequently contact FSIC agencies with requests to invite people with sensory loss and from the Deaf Community to be involved in proposed public consultations. The initial decision on who should be consulted and how is therefore taken by FSIC agencies and not service users.

Weighing this up against the human resource implications of staff within the FSIC agencies the research findings support establishing an independent joint user group within FSIC that could develop services both internally and externally for people with sensory loss and from the Deaf Community.

4 Section 4 - The Pilot Consultations in Practice

When planning the consultations, the research team agreed that both pilots would address the responses from the focus groups and interviews on “What did they think works well?” and “How can the barriers be overcome?” All the practical issues raised in Section 5 of this report were addressed by asking participants to complete a booking form.

An independent facilitator conducted the informal pilot and one of the representatives from the professional agencies facilitated the formal pilot. A graphic facilitator assisted with the informal pilot consultation. A minute-taker recorded the main points from both the consultations.

The informal pilot was co-ordinated by two of the community researchers while the formal pilot was co-ordinated by one of the community researchers and the team’s administrative support worker.

4.1 Informal Pilot

The venue, the Carnegie Leisure Centre, in Dunfermline was chosen because the research team were aware that it was not fully accessible. By using this venue the research team wanted to establish whether people would comment on the accessibility after taking part in an exercise class.

The co-ordinators had visited the venue beforehand and created a list of issues that were sent to the participants as areas they may wish to comment on during the consultation period. During this visit the co-ordinators had established that orientation around the building would be difficult for people with sight loss and sighted guides would be required.

The decision to use a physical activity on exercise bike machines within a leisure centre for the informal pilot was taken up because the Fife Healthy Living and Sensory Awareness Project were promoting physical activity through cycling. An interest in cycling for people with sensory loss had therefore been identified through the work of this project. As a result of this, the pilot’s co-ordinators were able to invite people who they knew from previous cycling events. This had an overall effect of cutting down the time required to find people with sight loss and from the Deaf Community.

However, the co-ordinators recognised that they had few people to ask who were hard of hearing and no one from the sensory loss/multiple disability group. They therefore invited the hard of hearing representatives and RNIB Scotland's representative to follow this up for them.

The participants with sight loss were invited to meet before the day of the event to discuss the aim of the event and how they could assist the co-ordinators. They all accepted this invitation. The Deafblind and hard of hearing participants were seen or telephoned individually and accepted the invitation to participate in the event. Two people with sight loss and multiple disabilities were invited to attend this event but due to the date and time of the event were unable to attend.

Sensory awareness training, sighted guide and an access audit were offered to the leisure centre before this event. As a result of this one of the instructors attended a sensory awareness and sighted guide training session. The other instructor was a parent of a child with sensory loss. It should be noted that usually exercise sessions only have one instructor. On request from the pilot co-ordinators the leisure centre agreed to have two instructors at this event.

See Appendix 1 for a breakdown of target communities and support staff requirements.

The independent facilitator and graphic facilitator were the only people who had little or no experience of working with people with sensory loss and from the Deaf Community. The observers felt the method used to consult the group (by asking individuals one at a time) discouraged open discussion. However, this gave everyone the opportunity to speak.

Participants completed a flipchart evaluation at the end of the session. This included questions relating to the consultation and exercise sessions as well as specific questions about the venue, leisure centre staff, instructors, the planning and organisation of the events, and more open questions about joint consultation.

Responses to these questions were positive. The majority of participants recorded that this experience was a good one, for example, in response to "Do you want to take part in another consultation session?", all said yes and the recorded comments were:

“It allows us to have our say.”

“Yes, beneficial to me and to others.”

In response to “Did you think it was important to take part in this event?” all agreed and the comments recorded were:

“It is important to give our views so that things can be improved for everyone.”

“It was good being with people with other impairments.”

“Yes, - if its going to improve the facility – I hope it will.”

On a less positive note, the response to “Did the instructors use clear communication?” six people said yes, three said no. The additional comments recorded were:

“Mix of instructor’s voice and loud music was hard.”

“Instructor’s voice was distorted.”

There was a disappointing response from leisure centre staff with no returns of evaluation forms and only one from the 2 instructors.

4.2 Formal Pilot

This pilot focused on a current NHS Fife project entitled “Patient Focused Booking in NHS Fife”. It was co-ordinated by one of the community researchers and the administrative support worker. Their role was to advise NHS Fife on the things they needed to have in place for effective consultation with people with sensory loss and from the Deaf Community. The joint consultation discussed the workings of the proposed new system.

The presenter received advice from the co-ordinators about delivering information to people with sensory loss and from the Deaf Community. This was received positively by the presenter. The research team, however, recommends that anyone delivering a presentation to people with sensory loss and from the Deaf Community attend a sensory awareness training session before the event.

The feedback from this consultation was very positive. Participants asked questions and NHS Fife recognised where improvements could be made to their proposed system. While there were some concerns raised, the research acknowledged that this could be because the organisers, presenter, observers and participants were all experiencing this form of consultation for the first time.

See Appendix 1 for a breakdown of community involvement and support staff requirements.

On the day of the consultation there were practical issues that needed to be addressed before the presentation could begin. These included:

- a faulty loop system;
- the seating arrangement – this affects communication with people using BSL Interpreters and Lip Speakers;
- blind people speaking while BSL Interpreters were signing to Deaf People.

The faulty loop system was rectified. The seating arrangement is a practical issue that presenters need to be aware of. With hindsight the organisers felt the issues relating to signing while blind people were speaking could have been overcome by informing the group at the beginning of the session that BSL Interpreters would be signing and there may be a slight delay between people speaking.

The organisers and presenter commented on the length of time it takes for questions to be interpreted and answers provided through a BSL Interpreter. When setting-up a consultation, time needs to be allowed for the slight delay that occurs when BSL Interpreters are communicating with BSL Users.

When asked about the use of the PowerPoint presentation, the presenter recognised that this particular PowerPoint presentation was of little help to people with sight loss and from the Deaf Community. BSL Users need to look at the BSL Interpreter while some hard of hearing people need to look at the Lip Speaker or lip-read and few people with sight loss can see the presentation. The research acknowledged that this is something that presenters need to be aware of when considering the layout of a room and the communication needs of those taking part.

4.3 Reflections from the Pilots

Our research found a difference of opinion between the participants of the two pilots about the benefits of joint consultation but we feel that this was due in part to the level of previous engagement of the two sets of participants. Where the informal pilot's participants knew each other or had an interest in cycling, the formal pilot's participants were meeting for the first time.

This finding leads us to conclude that it may be better in some cases to split people with sensory loss and people from the Deaf Community into separate consultation groups. However, as long as everyone is aware of the needs and practicalities of running a joint consultation it does have positive outcomes.

5 Section 5 – The Practical Issues

5.1 Introduction

All plans for research or consultation require time. When consulting people with sensory loss and from the Deaf Community extra support is required and time needs to be allowed for this. For example a British Sign Language (BSL) Interpreter needs to be booked at least 2 weeks in advance of a meeting. This section provides information on the practical issues arising from organising a joint consultation for people with sensory loss and from the Deaf Community and how this affected the research team's planning procedures.

5.2 Publicity Material

The preparatory time taken to find participants for any consultation is costly and time consuming. The research team therefore felt it was important to ensure that any publicity material about their research needed to be clear and understood by all people with sensory loss and professional agencies. (The latter may be able to assist with finding people who would like to take part in consultations.) For example, information should include graphics to assist BSL Users and be available in accessible formats for people with sight loss.

5.3 Communication and Mobility Support

The research team considered all areas of support required for people with sensory loss to ensure they were fully involved in joint consultation. All participants were provided with a booking form that gave them a choice of requesting the following support:

- Loop System;
- BSL Interpreters;
- Lip Speakers;
- Note-takers;
- DeafBlind Guide/Communicators;
- Sighted Guide;
- Transport;
- Accessible information.

5.4 Loop System

The research team was able to use the Fife Sensory Impairment Centre. This Centre has a working loop system in its main meeting rooms. However, the interview room that was used for the hard of hearing focus group does not have a working loop system. The portable loop system was therefore used on this occasion. Many venues do not have this equipment installed and a portable loop system needs to be booked through a professional organisation to assist people who are hard of hearing to participate in consultation.

5.5 British Sign Language (BSL) Interpreters and Lip Speakers

BSL Interpreters are professionally qualified to assist people from the Deaf Community to communicate with English speakers. Similarly Lip Speakers are professionally qualified to assist people who are profoundly deaf but not BSL Users to communicate. BSL Interpreters have been booked throughout this research and Lip Speakers were requested for the formal pilot consultation.

5.6 Note-takers

This role should not be confused with a minute-taker who takes notes of a meeting. A Note-taker is a professionally qualified person who is specifically booked for an individual who is profoundly deaf or hard of hearing. A verbatim report of the meeting is produced for the individual and given to them at the end of a meeting. This is a useful aid to communication for some participants who are hard of hearing or profoundly deaf. A Note-taker was requested for the formal pilot consultation.

5.7 DeafBlind Guide Communicator

A DeafBlind Guide Communicator is a professionally trained person who can aid communication and guide a person who is DeafBlind. DeafBlind communicators can be booked through professional organisations, for example, DeafBlind Scotland. The FSIC research included several people who were DeafBlind in their focus groups and pilot consultations. None of them chose to have a DeafBlind Guide Communicator.

5.8 Sighted Guide

Sighted Guides are a human resource that assist people with sight loss to orientate a building or local environment. There are specific techniques for guiding people up and down stairs, through doors and to chairs, to name but a few. Professionally qualified mobility officers for people with sight loss teach these techniques. There are currently two ways of booking Sighted Guides. The first is to use volunteers who have been specially trained. On the other hand Sighted Guides can be booked through a nursing agency. Throughout the research period, the FSIC research team used volunteers. However it should be recognised that the team knew each other and were working with people who had experience of sighted guide techniques. It is important to ensure that staff and/or volunteers are trained.

5.9 Transport

The research team recognised that due to the orientation issues mentioned above and the difficulties arising for people with sight loss in using public transport that participants should be offered transport from their home to venue and return. This was accepted by the majority of people with sight loss taking part in the focus groups and pilot consultations.

5.10 Accessible Information

Accessible information, sometimes referred to as “alternative formats” or “preferred formats” is a method of ensuring that people with sight loss have an opportunity to receive any information that will be presented in clear print or in PowerPoint presentations and overhead slides. If information is not made accessible to people with sight loss they will be excluded from the consultation. The FSIC research team therefore ensured that their booking form gave participants the choice of receiving information in clear print, large print, audiotape, Braille or electronically.

5.11 A Final Word

The research concluded that accessible information and communication is the key to a successful consultation with people with sensory loss and from the Deaf Community. It is time consuming to prepare and human support mechanisms as well as specialist equipment and software need to be in place to address these issues.

6 Section 6 – Recommendations

As a result of doing this research we recommend:

- Establishing a joint service user group to consider all requests received by FSIC agencies (and other similar bodies) to consult people with sensory loss and from the Deaf Community.
- That establishing the joint service user group will also provide a forum for joint consultation.
- FSIC agencies increase the profile of their services by promoting and distributing their publicity material more widely.
- Sensory awareness and sighted guide training for all who are involved in joint consultation with people with sensory loss and from the Deaf Community.
- Putting in place a mechanism that will ensure that all information is accessible to people with sensory loss and from the Deaf Community. This may include providing BSL Interpreters, taking advice about producing information in plain language and graphics, producing information in Braille and audio tape.
- Groups wanting to carry out joint consultation acknowledge the time it takes to prepare for meetings, everything takes longer!
- Groups carrying out joint consultation should be clear that staff time, administrative support and resources have a financial implication and should be included in applications for funding.

7 Section 7 – References

Arnstein S R, (1969), A ladder of citizen partnership, *Journal of the American Planning Association*, 35 (4), p 216-24

Ridley J, Jones L, (2002), *User and Public Involvement in Health Services: A Literature Review*, Edinburgh: Partners in Change, SHS . Trust

Bourne S, Spooner D, Calder C, (September 1998), *Sensory Service Users – Unseen Unheard – facing the realities of participation*, Living Options, Devon: The Sensory Project

8 Appendix 1 Breakdown of Community Involvement and Support Staff Requirements

8.1 Focus Groups and One to One Interviews

<u>Target Community</u>	<u>Focus Group</u>	<u>Interviews</u>
People with sight loss	4 out of 6 acceptances actually attended	5 (3 out of this 5 had additional needs)
Deaf People	2 out of 5 acceptances actually attended	0 out of 4 acceptances actually attended
Hard of Hearing Group	4 people attended	None
DeafBlind	None	None
Professionals	9 people attended	None

Two BSL Interpreters were booked for the focus group with BSL Users.

8.2 Informal Pilot

Target Community	Invited	Accepted
Deaf Community	9	2
Hard of Hearing	4	1
DeafBlind	3	3
Visually Impaired	3	3
People with Sight loss and multi disability	2	0

On the day of the informal pilot the support staff and equipment requested was:

- 2 x BSL Interpreters
- 2 x Sighted Guides
- 1 x Independent Facilitator
- 1 x Graphic Facilitator
- 1 x Minute-taker
- 1 x Portable loop system
- Transport.

8.3 Formal Pilot

Target Community	Invited	Accepted
Deaf Community	7	4
Hard of Hearing	5	3
DeafBlind	1	1
Visually Impaired	6	6
Parent of people with sight loss and multi disability	2	1

The support staff and equipment requested was:

- 2 x BSL Interpreters
- 2 x Lip Speakers
- 1 x Note-taker
- 1 x Sighted Guide
- 1 x Loop system
- Transport

9 Appendix 2 – Checklist

9.1 What Needs to be Done Beforehand?

- Be clear about the purpose – why you're doing it and what's in it for you.
- Plan properly – allocate time, it takes longer than you think.
- Must be timely and relevant.
- Facilities must enable everyone to participate – e.g. make sure loop systems etc are available before it starts.
- Tell people in plenty of time – send out invitations, letters.
- Organise awareness raising/training among group and the service before the event.
- Be clear in all communications – simple language, pictures, illustrations.
- Have a named contact point.
- Information format presented in different languages – BSL, lip-speaker, Deaf/blind, ethnic minority languages.
- Allocate funding - ££££.
- Arrange to have an impartial facilitator.
- Think about transport needs and how to meet them.
- Venue accessibility – is it necessary for the venue to be central? How relevant is the venue for the type of event you are organising? Venues may not be accessible but can barriers be overcome for the consultation?

9.2 What Needs to be Done During?

- During the event evaluate facilities to make sure everyone is able to participate – are loop systems working? Are people taking part?
- Make all communication clear.
- Some events need to go out to existing groups.
- Some consultation should involve people on a one-to-one.
- Some consultation should use the power of groups or collective action.
- Have an independent facilitator for the event.
- Make sure there is more than a single person from each community of interest (not isolated).
- People taking part must get something out of it.

9.3 What Needs to be Done After?

- Feedback
- Circulate report in accessible formats
- Monitor and review
- Tell people what's going to happen.

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This report is available on request in alternate formats, including large print, Braille and audio.