

PP HOW WAS IT FOR YOU??

Thursday 29 August 2002
10.00 am - 4.00 pm

Thistle Hotel
36 Cambridge Street, Glasgow

•
This conference is free

This one day conference, organised by the Scottish Executive in partnership with the Scottish Council on Deafness, NHS Greater Glasgow and Partners in Change, is an opportunity for the Scottish Executive to hear your views on the accessibility of services.



- What is working well?
- What you would like to see changed?
- What would make access to services easier for people who are DEAF, DEAFBLIND or HARD OF HEARING?



The Scottish Executive is committed to making health service accessible to everyone.

•
Sign language interpreters and lip speakers will be available at the conference.
Reasonable travel and accommodation expenses will be paid to anyone who is unwaged.

If you would like to attend please complete and return the attached booking form by Wednesday 14 August 2002 to Justine Davidson, SHS Trust, 1a Washington Court, Washington Lane, Edinburgh EH11 2HA.

Tel: 0131 538 7717 Fax: 0131 538 7719 Text telephone: 0131 477 3684
Email: jdavidson@shstrust.org.uk



SCOTTISH EXECUTIVE



HOW WAS IT FOR YOU?

Thursday 29 August 2002
10.00 am - 4.00 pm

BOOKING FORM

Please complete a separate booking form for each delegate and return to Justine Davidson, SHS Trust, 1a Washington Court, Washington Lane, Edinburgh EH11 2HA by Wednesday 14 August 2002

I would like to attend the conference

I will not be able to attend the conference but please keep me informed of future events

Name

Address

..... Postcode

Telephone

The venue is fully accessible and lip speakers and sign language interpreters will be present. I have the following specific requirements

.....

.....

I will require travel expenses from to the venue .
in Glasgow, which I estimate to be

I am unwaged and I require accommodation to be booked for me for the night of
Wednesday 28 August 2002.

Health and wellbeing; learning from people's own stories

Monday 14th October 2002

Please complete and return, by 13th September 2002,
to James Henderson at Partners in Change, SHS Trust,
1a Washington Court, Washington Lane, Edinburgh, EH11 2HA.
Tel. 01 31 538 7717, Text tel. 01 31 477 3684, Fax 01 31 538 7719

I would like to reserve a place at this meeting

Name

Organisation (if relevant)

Address

..... Postcode

Tel Text tel

Fax Email

The venue is fully accessible. An induction loop will be provided.

Interpreters will be present – please tell us below what interpretation services and support you will need.

Reasonable travel expenses for the meeting will be covered but need to be discussed in advanced.

I have the following requirements

Please complete a separate form for each delegate. Photocopies will be accepted or telephone SHS for more copies of this leaflet.

Health and wellbeing; learning from people's own stories

Monday 14th October 2002

9.30 - 1.30

**Centre for Independent Living,
117 / 127 Brook Street, Glasgow
lunch will follow**



Partners in Change is organising a meeting to look at a new research project which will work with deaf people, people who are hard of hearing and deafblind people, to find out about their experiences of health services, and what improves their health and sense of wellbeing.

- Are you deaf, hard of hearing, or deafblind?
- Do you use health services and have something to say about your experiences?
- Do you want to find out more about what others think?
- Do you have views that you would like to express about other circumstances in your life that affect your health and wellbeing – perhaps your experiences of employment, housing, education?



Partners in Change is a Scottish Executive initiative that is developing the involvement of people using health services and the public within the NHS in Scotland. We are looking to work alongside people who are deaf, hard of hearing or deafblind to:

1. Raise awareness amongst health services and the wider community of the experiences of people who are deaf, hard of hearing or deafblind in managing their own health and using health services: in particular to use these experiences to support health services to work in partnership with the people using the services.
2. To use Professor John McKnight's five determinants of health (see box) as a starting point for asking deaf people, people who are hard of hearing and deafblind people about their lives and what improves their sense of wellbeing and health.

Professor John McKnight, Director of Community Studies, Institute for Policy Research, at Northwestern University, Illinois, USA talks of five determinants of health:

- 1 Our individual behaviour such as eating, drinking, smoking, exercise
- 2 Social relationships quality of contact with family, friends, others
- 3 Our environment the air, our communities
- 4 Our economic status poor health and poverty are linked
- 5 Access to medical care

We are looking for deaf people, people who are hard of hearing and deafblind people to work with us. The roles people could take include:

- advising on what needs to be explored
- interviewing other people who are deaf, deafblind or hard of hearing, health professionals and other relevant people
- being interviewed
- editing the stories we collect from people
- thinking through the information gathered to understand it in more depth
- talking to others about what we have found out.

We will provide support for any of the roles that people choose to take on. Expenses will be covered, and payment made for particular work undertaken.

The information gathered will be used to produce two publications that tell the stories of people who are deaf, hard of hearing and deafblind in using health services and in managing their own health and wellbeing.

Interested?

The meeting on 14th October 2002 is for everyone who is interested to develop the ideas further and find out more about the roles that people could take in the research. If you would like to come along please complete the attached slip and send it back to us.

If you'd like to know more, or have ideas to suggest, comments to make, and contacts to pass on, please contact James Henderson at SHS Trust.

How was it for you?

Thursday 29th August 2002

Thistle Hotel, Cambridge Street, Glasgow

9.30 **Coffee and registration**

10.00 **Welcome and introduction**

Chair Dr Andrew Fraser, Deputy Chief Medical Officer, Scottish Executive Health Department

10.10 **Setting the Scene**

Pam Whittle, Director, Health Improvement Division, Scottish Executive
Anne Connor, Programme Manager, Partners in Change
Lilian Lawson, Director, Scottish Council on Deafness

10.30 **Workshop 1 - What would make access to services ideal?**

11.30 BREAK

11.50 **Feedback from workshop sessions**

12.10 **Improving the Health of Deaf People**

Michael Davis, Health Promotions Officer, Greater Glasgow NHS Board

12.30 LUNCH

1.30 **Workshop 2 - Reaching the ideal**

3.00 BREAK

3.20 **Feedback from workshop sessions**

3.40 **The way forward**

Dr Andrew Fraser, Deputy Chief Medical Officer, Scottish Executive Health Department

Anne Connor, Programme Manager, Partners in Change
Lilian Lawson, Director, Scottish Council on Deafness
Drena O'Malley, Chief Executive, Deafblind Scotland

4.00 Finish

PP HOW WAS IT FOR YOU? 99

At this one day conference to hear people's views on the accessibility of services, there were two workshop sessions. The graphic notes taken at each workshop have been collated and sorted into themes. We have produced a separate leaflet for each of the seven main themes, with the key points highlighted and people's actual words reproduced. On the back page of each leaflet there are the ideas people had for improvements that might be made to allow them to access services more easily.

Theme 1 Individual treatment, care and support

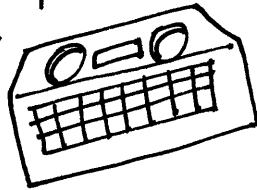
Under this theme we found that people talked about many different issues. The main points people raised were:

- People experienced difficulty in making an appointment with their GP.
- People find it very difficult to change appointments once they are made, particularly if they already have an interpreter booked.
- It was common for people to 'miss' the call to go in to the doctor or nurse's office once they were in the waiting room.
- Although GPs and other staff can think that they listen well, it is deaf people's experience that often this is not the case.
- Deaf people don't always want to use their family as interpreters and sometimes they feel afraid to demand an interpreter or to say they don't understand.

Some of the things people said

Appointments

no one answers the text phone



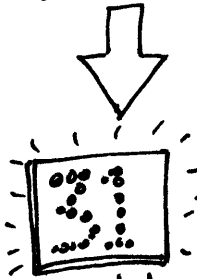
Appointments are too short

The text phone doesn't work!!

staff don't always know how to use them...

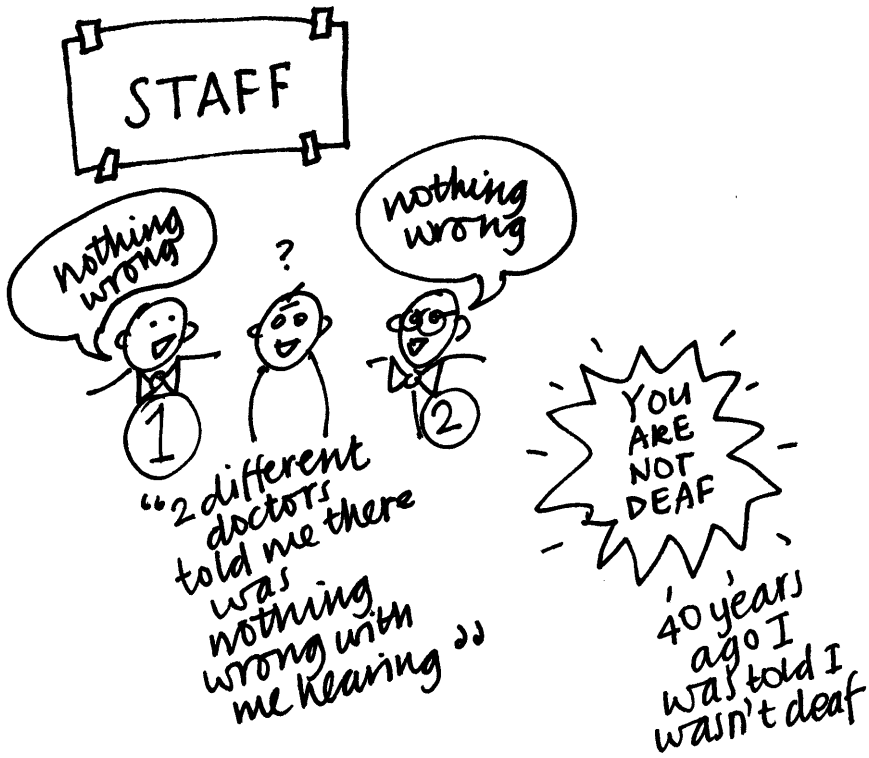
I know how but it takes too long...

They shout out names - and we can't hear



...need a number system





~~⊗ ⊗ ⊗~~

If you are deaf and have sight problems people don't see your deafness

DEAF AWARENESS training today 9.00

← compulsory training for GPs & other health care staff...

↓

raise awareness of receptionists in GPs & teach basic BSL

Things need to be written down for people ~ some GPs don't do this

Have at least 1 BSL GP in each surgery

How can I help?



Theme 1 • Individual treatment, care and support

Improvements that might be made

Different ways of communicating with people could be developed and used in public waiting areas. These might include:

- Use of an electronic screen to alert people to their appointment.
- Giving people a vibrating pager as they check in for an appointment.
- Asking staff go up to the person and let them know they can go in for their appointment.
- Indicating on appointment cards that an interpreter is booked.

Other improvements to communication were suggested:

- Include an ID system on patients records so GP or reception staff ties interpreter into appointment.
- Encourage people to take a hearing friend, who can sign for them, along to appointments.

Deaf awareness is a subject that appears under other themes. Some of the issues that people wished to see addressed were:

- More training for staff at all levels of a service provider. This should include frontline staff, as well as GPs, and also senior management in the NHS and the Scottish Executive.
- Training to help staff to understand how to work with interpreters and to know the range of support services available. This could help staff to change and develop positive attitudes.
- Deaf awareness training should be accredited (CPD) by GP ongoing training scheme so that GPs are motivated to take it up.
- Shadowing could be encouraged and seen as an important training tool.
- Support for deaf awareness training should be a policy decision.
- Guidelines and checklists for communication should be developed.

This is one of a series of leaflets produced as part of the 'How was it for you?' conference on 29th August 2002. The full conference report is available from SHS Trust, 1a Washington Court, Washington Lane, Edinburgh, EH11 2HA, Tel: 0131 538 7717 Email: general@shstrust.org.uk

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Theme 2

Improving the availability and effectiveness of services

The main points people raised as part of this theme were:

- People experience long waiting times for audiology services.
- Not all audiology staff know sign language.
- There is limited availability of digital hearing aids on the NHS.
- Other health services besides GP surgeries are important (for example dentists and opticians).
- It is important for people to have access to sexual health information.
- People would like loop systems in the home, but can't always afford them.
- There is limited availability of loop systems in GP surgeries and in other health services.
- People can have to wait a long time for information - the system needs to be more responsive.
- It is important to people that the NHS (not the voluntary sector or individuals) pays for the cost of interpreters.

Some of the things people said

On digital hearing aids:

'It seems easier to get an implant than to get a digital hearing aid'

'An RNID survey on 'does a digital hearing aid help?' found an average of 40% increase in hearing but I had to pay for it and I think my hearing has increased by 60%'

'It's expensive'

'Money should be found to give this to everyone'

"A digital hearing aid may not help people who are profoundly deaf'...so don't put all your eggs in one basket'

Staff issues:

'Often people in the audiology department can't sign and have poor attitudes to people who are deaf'

'We should have a hearing therapist in each setting'

Issues to do with information:

'There should be (more accessible) information on sexual health for deaf people'

'We need information to be circulated and then chased up by individuals to make sure it evokes action'

Health Issues:

'Deaf people need education on general health issues'

'Out with Glasgow and Edinburgh little education about health awareness issues'

'There should be continuing rehabilitation of the deaf person. Who looks after that person after their first hospital appointment and they have been given the aids they need? If that person had high blood pressure their health care would be continued, but not for hard of hearing people'

'We need a positive discrimination to be in force in hospitals'

Services in general:

'If you can't provide services to a deaf person, you are not providing good care'

'We talked about mainstreaming services'

Other comments people made:

'I got the wrong kind of help - a home help who worked fewer hours than I paid and I didn't want a home help!'

'Loop systems should be available and working everywhere'

'It is not dignified to always have to ask'

'We need more audiologists, lip-reading classes, volunteers visitors'

Improvements that might be made

People suggested some improvements that could be made to services:

- There is a need for more audiologists.
- There should be volunteers to help people with hearing aids (as long as issues of quality and safety are taken into account).
- Audiology staff should be taught sign language.
- There should be greater availability of loop systems, including portable ones

There were also suggestions about how funding and resources could be targeted:

- Generic funding is needed for sign interpreters and communication technology.
- There should be more resources made available to speed up people's access to information.

Also mentioned was the need to make services mainstream:

- NHS Boards and NHS Trusts should make services for deaf people part of the mainstream - accessibility to services for deaf people should be a central part of the planning process, rather than being 'bolted on' afterwards.

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Theme 3 Policy and National Levels

Under this theme we found that people had lots of ideas about how to make improvements, and what needs to be different, in this area. The main points raised by people were:

- There is a need for British Sign Language to be accepted as a minority language.
- There should be greater involvement of deaf people in planning services, including at the level of the Scottish Executive.
- It is vital for there to be greater clarity in policy so that people know what they are entitled to, and for evaluation of what happens, to support further development.
- The Disability Discrimination Act (1995) needs a strong lead with a definable leadership. An amalgamation of rights commissions would solve this - Equalities Commission, DRC, ERC, EUC.
- Establish a Centre of Excellence supporting deaf awareness.
- Use Scottish Executive Health Department Letter (1998 or 1999) to support the rights and equality of deaf blind people.
- The Scottish Executive Equalities Unit should involve more deaf people, and deaf awareness should be raised within the Scottish Executive.
- Parliamentary work - making greater connections between deaf people, their organisations, and the parliamentary group.
- Policy is clear about what deaf people are entitled to; what the priorities are in relation to technology, communication, deaf awareness, and who has the responsibility to make it happen.
- There is a need for more funding.
- Evaluation should be part of the process - make a commitment to see what's happened/changed in a year's time.

Some of the things people said

On using the introduction of the third stage of the Disability Discrimination Act (1995)

'Many Disability Rights Commission officials themselves have disabilities and they are writing 'Good practice guides''

'DDA means deaf awareness will have to be taken seriously'

'In 2004 the DDA will apply to the physical environment of services'

'We can all do something'

'Follow the model used by Greater Glasgow Health Board'

Increasing the use of British Sign Language (BSL) in the health service:

'Health services to accept BSL as a language'

'Make training in communication compulsory and performance review it'

'Children (need to be) taught BSL in schools'

'It must be mandatory that diverse communication needs are taken into account'

The importance of a team including deaf people attending the European Social Forum for Mental Health and Deafness Conference 2003:

'We have to make links across national boundaries'

Deaf people should be more involved in planning:

'We should be looking at trying to involve deaf people more at a policy level'

More deaf people should be employed in the health service:

'Someone who is deaf or has experience of deafness could work as a listening post at the Scottish Executive'

'Replicate the Greater Glasgow NHS Board model of having deaf community workers as NHS Board staff'

Improvements that might be made

Pages 1-3 of this theme show that people generally talked about what needs to be different in the area of policy and issues for people who are deaf. There are no specific 'improvements that might be made' - the whole of this theme is concerned with improvements, and how to make things different, based on the useful and interesting ideas generated by the people at the conference.

PP HOW WAS IT
FOR YOU? 99

Theme 4 Improving communication

The main points arising from discussion of this theme were:

- Technology can be used to aid communication.
- There can be problems with interpretation (eg, deaf people don't always want other members of their family to interpret for them, particularly when there are private, confidential issues to discuss).
- Deafblind people need one-to-one communication.
- People should be encouraged to speak more clearly.
- Written information is not always easily accessible.
- The availability of things that help can be limited (eg lip-speaking classes) and the cost of courses plus the travel can be prohibitive.

Some of the things people said

Technology can be used to aid communication:

'Technology can help to enable better services but who pays for the technology and who pays to maintain it?'

'A video telephone helps with other communication difficulties - minority ethnic languages, for instance - it also means you can use an interpreter from further afield for sensitive issues (for example sexual health)'

'More advances in technology - voice recognised'

'There was a lack of awareness of what technological aids could be got. GPs were not aware of this'

'There should be greater provision of newer technology'

The use of interpreters can help, although there are issues to take into consideration:

'Nothing will beat people being present''We should have interpreters and guides to take to meetings'

'Health professionals need to understand what an interpreters role is and how to use communication support'

'Using an interpreter was OK but the GP refused to pay – I had a 5 year fight. I do not have to pay for an interpreter in hospital - however the hospital should be booking interpreters or lip speakers - people shouldn't have to book interpreters themselves'

'There are not enough interpreters'

'Interpreters currently have to pay for their training'

Written information is not always up to scratch:

'It should be jargon free and accessible to individual needs'

'Today (this consultation conference) is not deaf friendly - i.e. written material is produced in other languages and in Braille, but not in British Sign Language'

'Most of the leaflets are complicated and difficult to read. We need to make them more 'deaf-friendly''

Lip-speaking classes can be hard to find and the cost of the course and travel to the course can be very expensive:

'We need more lip-reading classes and more communication'

'Lip-reading can be very difficult'

'We need ore lip reading classes, more hearing therapies and therapists'

Problems with communication:

'If you are deaf blind then written word and text phone is of no value - the MEL 1998 (ie Scottish Executive Health Department letter) for one-to-one support should be in place'

'I can only communicate face to face - and we're not given time for that'

'Communication problems can arise in different situations - for example when dentists wear masks; when opticians use strong lights; or following surgery or treatment in hospital - with a drip in both arms you cannot sign'

Deaf people can feel very isolated when they are unwell:

'Cancer is a very isolating experience if you are deaf'

'British Sign Language users may not know why they are going to hospital'

Some other comments that were made in this discussion:

'We need to have access to services 24 hours a day, 365 days a year'

'People's attitudes are a barrier - deaf awareness training is a tool to help combat this'

'We should work with the Executive to figure out who pays for what'

(Re: 'spoken English')

'We need to advocate for better spoken English'

'Doctors and nurses should be taught to enunciate'

Improvements that might be made

Around technology:

- Improving 'immediate' communication - using video-telephone in surgeries, more use of loop system, public text phones in GP surgeries etc.

In interpretation services:

- New approaches to interpretation services - interpreters from other regions or parts of the UK could be used to provide support on confidential and sensitive issues.

Suggestions on how to improve written material:

- Work with people to produce 'deaf friendly' leaflets; make it jargon-free; use strong pictorial content.

Some other suggestions for improvements:

- More locally accessible, free or affordable lip-speaking classes.
- Deaf people want to be involved in community access panels
- Develop a recognisable deaf 'symbol'.
- Video telephone technology would be useful (but it needs to be funded).
- Sign language should be taught more widely.

PP HOW WAS IT FOR YOU? 99

Theme 5 Deaf awareness and education

- GPs need encouragement to attend deaf awareness training.
- Money needs to be put into supporting the training.
- Wider public education work is also needed.
- There is a need for more training for service providers at all levels.
- There can be a stigma attached to having a disability.
- Deaf people working within organisations should build the profile of deafness and inform practice. This is part of a series of leaflets produced as part of the 'How was it for you?' conference on 29th August 2002. The full conference report is available from SHS Trust, 1a Washington Court, Washington Lane, Edinburgh, EH11 2HA, Tel: 0131 538 7717 Email: general@shstrust.org.uk This is one of a series of leaflets produced as part of the 'How was it for you?' conference on 29th August 2002. The full conference report is available from SHS Trust, 1a Washington Court, Washington Lane, Edinburgh, EH11 2HA, Tel: 0131 538 7717 Email: general@shstrust.org.uk
- There is a need to educate the public and society at large. Some ways of doing this are: raising deaf awareness in schools and in the media; teaching British Sign Language in primary schools to children; using positive images of deaf people in promotional and educational materials and in the media.

Some of the things people said

About deaf awareness:

'There's a low take-up of deaf awareness training when offered'

'There can be a risk of stigma in admitting to wearing a hearing aid'

'I went deaf and my own prejudice made me feel bad'

'Acceptance of deaf people is important'

'People need to realise that they need deaf awareness training'

'Some of us have been telling you this for years - it's not being acted upon'

'I raised awareness with St. John's about access - I had a meeting with them a year later'

On GPs and deaf awareness:

'My problems stemmed from the attitudes of doctors'

'We need to give GPs food for thought'

'if people are expert clinical therapists how can we expect them also to be expert in many languages, as well as BSL?'

'Deaf awareness and basic signing should be a compulsory component of pre-registration and continual professional development for GPs'

'We could find a way for GPs to think of it as important to access deaf awareness training, perhaps by getting in on the ongoing GP training scheme (CPD) - however, points are needed to attract attendees (because if it's not approved it will not count towards their training requirements)'

'We need to get GPs to come to events like this'

Deaf awareness while people are training to become a professional:

'When people receive training, eg teachers, doctors, they should get standard deaf awareness training'

'There should be Disability Equality Training in employment law and education'

'All service providers need more training...and it needs to go to a high level - to the Scottish Executive. Then to the college for GPs, and then the training would filter down'

The need for public and society-wide education on deaf awareness, and how to do it:

'There should be training face to face with the people in charge'

'Education - in the widest sense'

'We should use positive imagery'

'There should be more deaf people on the TV'

'We can make people aware early on that they (too) could lose their hearing'

'There should be more use of subtitles and signers on TV - especially in HEBS and Scottish Executive adverts'

'We should teach children in primary schools about deafblind awareness'

'We put one of our workers into a primary school to teach hearing children BSL so that they can talk to deaf children'

Issues to do with money/funding:

'There is no budget to do deaf awareness training in social work'

'Money is a barrier for some things, but not everything'

'Something needs to be done to get money - we could use lottery fund'

'Surely we can find the money somewhere?'

'Money has been used as an excuse for a long, long time'

'Let's not stop at money'

'Money is spent on the wrong things'

Improvements that might be made

- Money should be put into deaf awareness training.
- Deaf awareness needs to start early - when people are at primary school.
- Positive images of deaf people should be presented.
- GPs and other professionals need training - it has to be made attractive to them.
- Society at large needs to be educated on deaf issues.

PP HOW WAS IT FOR YOU? 99

Theme 6 Partnership working

The main points arising from this discussion were:

- Self advocacy and assertiveness training should be supported.
- Shared learning is important.
- There is a need for people who are willing to learn, and organisations who are willing to learn.
- Interpretative and communication services and tools need to be developed, in order to allow deaf people to participate fully.

Partnerships between deaf people and the rest of the community:

- Being in touch with people/being part of a community - these things are part of keeping well and contribute to people's general well-being.
- Partnerships can help to change attitudes in the community - for example, deaf children being educated in mainstream schools, especially primary schools, can be a way of breaking down barriers for the next generations.

Some of the things people said

It's about all of us...

'People in power and with power should be willing to come and join us'

'We should involve all stakeholders, deaf people, families, deaf organisations, health services, the Scottish Executive and politicians'

'Need someone in power to (help) take it forward'

What deaf people can do:

'We need to take action'

'Lets not just moan'

'Self-advocacy and assertiveness and rights - it's about knowing what's available'

'Deaf people need assertiveness training'

'Deaf people need to make adjustments ... Deaf people need to ask for help'

'We all have to get involved - write letter etc; you need a thick skin to do this'

Sharing learning and working together:

'We should be sharing current good practice with voluntary agencies and mainstreaming by health boards with voluntary organisations'

'Go out and speak to people'

'Join community and voluntary groups'

'Share stories'

'Shadowing each other might be interesting'

'Complaints and suggestions - use the system - we also need to point out when people get it right'

Other comments on partnership working:

'To listen and learn'

'We have the power'

'They have the power to get involved (too)'

'Who's responsibility is it to make change happen?'

'Over and over again there is an awareness that many people are doing a good job but often they are not aware of what other services do'

Improvements that might be made

Please see pages 2 and 3 of this leaflet - people's comments make clear the improvements they think could be made and how things could be different.

Theme 1.

Individual appointments and consultations: the people attending the workshops were asked to explore what made for good services, what were the barriers to such services, and how services could be improved or changed to overcome the barriers. Many people spoke of the difficulties in simply making appointments, waiting for appointments, and then communicating successfully and confidentially once at the appointment. They also suggested many ways to tackle these present difficulties.

- ◆ **people experienced difficulty in making an appointment with their GP**

- ◆ **it can be very difficult to change appointments, particularly if you already have an interpreter booked**

‘no one answers the text phone’ or as some stated ‘the text phone often doesn’t work or staff don’t know how to use them’

‘Refusal of type phone calls as they take too long’

- ◆ **Waiting for appointments – it is common for people to ‘miss’ the call to go in to the doctor’s, nurse’s office**

‘out patient staff poorly reactive even just when telling you have arrived – they shout out names and we can’t hear names – need number system’

- ◆ **Meeting with staff** – GPs and other staff can think that they listen well but deaf people’s experience is often that this is not the case

‘2 different doctors told me there was nothing wrong with my hearing’

‘40 years ago I was told I wasn’t deaf’

‘If you are deaf and have sight problems people don’t see your deafness’

‘raise awareness of receptionists in GP surgeries and teach etiquette and basic BLS’

‘doctors and others should learn BSL as a language or at least one doctor in each surgery’

‘some GPs won’t write notes for deaf people to support their understanding during consultations’

‘(needs to be) written down for some people’

- **Deaf people don't always want to use their family as interpreters**

'as a parent emergency service is a phone service its no good to me – I can't access it – the doctor came and spoke to my son and ignored me – my son has to tell me what the doctor told him - he should be able to speak to me not my son.- children should not be used as interpreters'

- ◆ **sometimes deaf people feel afraid to demand an interpreter or to say they don't understand**

- ◆ **Staff knowledge and skills** – many nurses don't know how to put hearing aids in

'I meet nurses who don't know how to put hearing aids in ... many, many people know nothing about environmental aids available'

'Doctors need to be trained better' 'Its no longer than 6-8 hours at the moment'

' All services should undertake regular deaf awareness training ... (including) local authority sheltered housing'

' it should be compulsory for all GP's and other health care staff'

What should be different ...

Develop the use of electronic screen to alert people to their appointment, or a vibrating pager – or simply make sure staff go up to the person and let them know they can go in for their appointment.

‘one person said they had a digital electronic screen in one hospital he attended that registers the patients name and room number to go to. Members of the group felt that would be useful in all out patient departments’

Appointment cards should indicate that an interpreter is booked

‘appointments by fax or use mobile for messaging’ people acknowledged that this method could be open to abuse and suggested that it needs to be for use of deaf people only

Using signers on a video phone link - ‘video phone to signer’

Supporting reception staff in recognising people’s communication support needs - ‘ID system on patients records so GP or reception staff ties interpreter into appointment’

The service making it easy to use an interpreter - ‘we shouldn’t have to fill out a form for an interpreter (because of the) problem of extra expense ... and get a worse reputation if we miss an appointment’

Use of finger spelling - another suggestion was ‘staff who can finger spell names or an electronic system to let people know it is their turn

Working with the service - ‘I took a hearing friend who can sign for me’

Deaf Awareness training: (see more on deaf awareness in theme 4 on education)

- training is crucial for staff at all levels of a service provider; frontline staff including GPs need it, but also needed for senior management and the Scottish Executive
- the training would help staff to understand how to work with interpreters and to know the range of support services available
- it would also help staff to change and develop positive attitudes
- this training should be accredited (CPD) by the GP ongoing training scheme so that GPs are motivated to take it up and go to relevant events
- shadowing would be an important training tool.

‘the NHS (needs) to pay more to GP who has done deaf awareness training - has to come from top as a policy decision’

Guidelines/checklists produced to support staff in understanding the communication needs of deaf people

Theme 2.

Improving the availability and effectiveness of services: the people attending the workshops were asked to explore what made for good services, what were the barriers to such services, and how services could be improved or changed to overcome the barriers. Problems with present audiology services were identified, as well as the need for all services to be better prepared to work with deaf people. There was a clear need for better information, and for the NHS to pay for interpretation and communication services. People spoke of the need for the NHS to involve deaf people in planning all services so that the needs of deaf people were taken into account in providing any service – rather than providing different or special services.

◆ Long waiting times for audiology services

◆ Audiology staff not being able to sign

‘often people in the audiology department can’t sign and have poor attitudes to people who are deaf’

◆ Limited availability of digital hearing aids on the NHS –

‘it seems easier to get an implant than to get a digital hearing aid’

‘An RNID survey on ‘Does a digital hearing aid help?’ found an average 40% increase in hearing ... but ... I had to pay for it and I think my hearing has increased by 60%’

‘it’s expensive’

‘money should be found to give this to everyone’

‘digital hearing aid may not help people who are profoundly deaf’ ... so ... ‘don’t put all your eggs in one basket’

◆ Other services – don’t forget dentists and opticians, or, for instance, the importance of sexual health information

‘(more accessible) information on sexual health for deaf people’

‘I got the wrong kind of help – a homehelp who worked fewer hours than I paid and I didn’t want a home help!’

◆ loop systems in the home, people want them but can’t always afford them

◆ limited availability of loop systems in G.P. surgeries etc

'loop systems should be available working everywhere' 'it is not dignified to always have to ask'

- ◆ **Waiting times for information** – system needs to be more responsive
- ◆ **Who pays? - important for the NHS not voluntary sector or individuals to meet costs of interpreters** – one person has had a five year fight with GP about the cost of an interpreter

What should be different ...

more audiologists needed

volunteers to help people with hearing aids - as long as issues of quality and safety are watched for

audiology staff who can sign

health boards and trusts pulling services for deaf people into the mainstream and making accessibility to services for deaf people a central part of the planning process, rather than bolted on

generic funding is needed for sign interpreters and communication technology

Greater availability of loop systems including portable ones

More resources to speed up access to information - 'need information to be circulated and then chased up by individuals to make sure it evokes action'

Theme 3. (Julie, no concluding 'what needs to be different' in this theme as its all largely about what needs to be different. James)

Policy and National levels: the people attending the workshops were asked to explore what made for good services, what were the barriers to such services, and how services could be improved or changed to overcome the barriers. The start of the third phase of the Disability Discrimination Act (1995) in 2004 was seen as a particular opportunity. People spoke of the need for the acceptance of BSL as a minority language, and for greater involvement of deaf people in planning services including at the level of the Scottish Executive, perhaps through the development of a Centre of Excellence. It was vital too, for there to be greater clarity in policy so that people knew what they were entitled to, and for evaluation of what happens to support further development.

◆ **Using the introduction of the third stage of the Disability Discrimination Act (1995)**

It was acknowledged that many of Disability Rights Commission officials themselves have disabilities and that they are writing 'Good practice guides'

'DDA means deaf awareness will have to be taken seriously'

Needs a strong lead with a definable leadership amalgamation of rights commissions would solve - equalities commission DRC ERC EUC

'DDA 2004 will apply to the physical environment'

'We can all do something'

'follow the model used by Greater Glasgow Health Board'

• **Increase the use of British Sign Language (BSL) in the health service**

'health services to accept BSL as a language'

'make training in communication compulsory and performance review'

'children (need to be) taught BSL in schools'

'must be mandatory that diverse communication needs are taken into account'

- **European Social Forum for Mental Health and Deafness Conference 2003 – important for a team including deaf people to attend**

'make links across national boundaries'

- **Involve deaf people more in planning**

'it was felt that we should be looking at trying to involve deaf people more at a policy level'

- **Employ more deaf people in the health service**

'someone who is deaf or experience of deafness as a listening post at the Scottish Executive'

'replicate GGHB model of having deaf community workers as NHS Board staff'

- **Establish a Centre of Excellence** – supporting deaf awareness; supporting interpreting services, perhaps provided by video telephony, or using web cam;
- **use MEL (1998 or 1999) (Julie, I need to check out what this is, James)** to support the rights and equality of deaf blind people
- **the equalities unit involving more deaf people, and raising deaf awareness within the Scottish Executive**
- **Parliamentary work** - greater connections between deaf people, their organisations, and the parliamentary group
- **Policy is clear** about what deaf people are entitled to; what the priorities are in relation to technology, communication, deaf awareness, and who has the responsibility to make what happens
- **More funding**
- **Evaluation** – make a commitment to see what's happened/changed in a year's time

Theme 4.

Improving communication: the people attending the workshops were asked to explore what made for good services, what were the barriers to such services, and how services could be improved or changed to overcome the barriers. There was a clear need to improve interpretation services and to use technology such as video-telephony to support this. Likewise the communication needs of deafblind people needed to be prioritised. Written information needed to be simply, clear and free of jargon. More opportunities for staff and others to learn lipspeaking was also very important.

◆ Use of technology to aid communication

“technology can help to enable better services but who pays for the technology and who pays to maintain it’

‘video telephone – this solution also help other communication difficulties (minority languages, for instance) ... also means can use interpreter from further afield for sensitive issues eg sexual health’

‘more advances in technonology – voice recognised’

◆ Interpreters and families –

deaf people don't always want other members of their family to interpret for them, particularly when there are private, confidential issues to discuss

deaf people should'nt have to have their children interpreting for them at a consultation

‘nothing will beat people being present’

“Health professionals need to understand what an interpreters role is and how to use communication support”

◆ written word and text phones don't help deafblind people, they need one to one communication (MEL 1998)

‘If you are deaf blind then written word and text phone is of no value – MEL (1998) for 1 to 1 support should be in place’

'Have interpreters and guides to take to meeting'

'I can only communicate face to face' ' Not given time for that'

'need to have access to services 24hrs /day 365 days/year'

NHS24 not currently accessible but they are trying to figure out how it will work.
Chair of SCoD is on working party for NHS24

'People's attitudes are a barrier – deaf awareness training is a tool for this'

- **Encourage people to use clearer spoken English**

'We need to advocate for better spoken English'

'Doctors and nurses taught to annunciate'

- ◆ **written information not always easily accessible**

'jargon free and accessible to individual needs'

- ◆ **limited availability of lip-speaking classes – cost and travel can be prohibitive**

'we need more lip-reading classes and more communication'

'lip-reading can be very difficult'

What should be different ...

Improving 'immediate' communication – using video-telephony in surgeries, more use of loop system, public text phones in G.P. Surgeries etc

New approaches to interpretation services - interpreters from other regions or parts of the UK could be used to provide support on confidential and sensitive issues

'Work with executive to figure out who pays for what'

Work with people to produce 'deaf friendly' leaflets; make it jargon-free; use strong pictorial content

More locally accessible, free or affordable lip-speaking classes

Involvement in community access panels: 'group willingness to be involved in community access panels'

Develop a recognisable deaf 'symbol'

Theme five.

Deaf awareness and education: the people attending the workshops were asked to explore what made for good services, what were the barriers to such services, and how services could be improved or changed to overcome the barriers. Deaf awareness training and education related to deaf awareness was considered crucial. Presently many people working within health services and across wider society have little knowledge of what life is like for deaf people. Deaf people face stigma, and the process of going deaf brings self-doubt to people. Yet training is rarely taken up by services. GP's need encouragement to attend such training, money needs to be put into supporting the training, whilst wider public education work is also needed.

◆ Deaf awareness:

'There's a low take-up of deaf awareness training when offered'

More training for service providers at all levels

'(Risk of) Stigma in admitting to wearing a hearing aid'

'I went deaf and my own prejudice made me feel bad'

'Acceptance of deaf people'

'People need to realise they need deaf awareness training'

'Some of us have been telling this for years – its not being acted upon'

I raised awareness with St. John's about the access - had a meeting with them a year later.

My problems stemmed from the attitudes of doctors'

'need to give GP's food for thought'

What needs to be done ...

- ◆ **Money is needed** from social work departments to pay for deaf awareness training but social work budgets do not include this

'problem: there is no budget to do that training in social work'

'money is a barrier for some things not everything'

'social work don't' have the money to train staff in deaf awareness'

'something needs to be done to get money ... could use lottery fund'

'surely we can find the money somewhere'

'but money has been used as an excuse for a long, long time'

'let's not stop at money' 'money is spent on the wrong things'

- **GP's and deaf awareness**

'deaf awareness and basic signing should be a compulsory component of pre-registration and continual professional development.'

Find a way for GP's to think of it as important to access deaf awareness training, perhaps by getting in on the (CPD) by the GP ongoing training scheme (CPD) - points are needed to attract attendees as if not approved will not count towards training requirements

'need to get GP's to come to events like this'

- **Deaf people working within organisations to build the profile of deafness and inform practice**

- ◆ **Public and society-wide education** – raise deaf awareness in schools, in the media; teach BSL sign language in schools to primary children, use positive images of deaf people in promotional, educational materials and in the media; more deaf people on TV

'training face to face with people in charge'

'education – in the widest sense'

'positive imagery'

'more people on the TV'

'make people aware early on that they (too) could lose their hearing'

more use of subtitles and signers on TV – HEBS/Scottish Executive adverts

6.Partnership working: the people attending the workshops were asked to explore what made for good health services, what were the barriers to using such services, and how could services be improved or changed to overcome the barriers. Deaf people felt it was vital to involve them in the development of such services by:

- ◆ supporting self advocacy and assertiveness training
- ◆ developing interpretative and communication services and tools to allow deaf people to fully participate
- ◆ use of shared learning – a need for people and organisations who are willing to learn

What would make a difference ...

‘people in power and with power being willing to join with and come to ‘us’

‘involving all stakeholders, deaf people, families, deaf organisations, health services, Scottish executive, politicians’

“shadowing each other might be interesting”

‘Complaints and suggestions – use the system’ ‘Thank-you ... also we need to point out when people get it right’

‘Need someone in power to (help) take it forward’

‘We need to take action’

‘Lets not just moan’

‘Self-advocacy and assertiveness and rights – knowing what’s available’

‘Deaf people need assertiveness training’

‘Sharing current good practice with voluntary agencies and mainstreaming by health boards with voluntary organisations’

‘To listen and learn’

‘Deaf people need to make adjustments ... Deaf people need to ask for help’

‘We have the power’ ‘They have the power to get involved (too)’

‘Go out and speak to people’ ‘Join community and voluntary groups’ ‘Share stories’

'Who's responsibility is it to make change happen?'

7. Other quotes, blocks of quotes:

EXPERIENCES OF THE DAY:

'Great to be in a group where deaf people are the majority'

Priorities (of one workshop):

Technology
More interpreters and sign language
More money to shorten waiting times to information
Generic funding for signers and technology
More electronic note taking
Change attitude, society and stigma
Training on Awareness and BSL (G4)
We need more audiologists

Who has a role to play in this?

Deaf people
Extended family
Politicians
Support workers
Deaf groups
Scottish Executive

How high a priority are deaf issues?

Trying to make sure the voices of patients are being heard
Education need to be involved
Need to take a public sector approach
We've got to get our act together
Do we operate a safe service?
We need to make connections between good practice