

## CONSULTATION QUESTIONS

The British Deaf Association (BDA) is the largest Deaf organisation in the UK that is run by Deaf people; united by shared experiences, history, and, most importantly, by British Sign Language (BSL).

Since 1890, the BDA's long standing commitment has been to ensure that the language, culture, community and heritage of Deaf people should be effectively protected by valuing the rights of Deaf people, with all their diverse experiences and abilities, and the usage of BSL.

The BDA wishes to see a society where sign language users have the same rights, responsibilities, opportunities and a quality of life like everyone else.

Our mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, leading to the full social inclusion for Deaf people. This will be achieved through:

- Improving quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL;
- Establishing bilingual education for Deaf children.

According to the Scottish Council on Deafness, the number of people in Scotland whose first or preferred language is BSL was estimated by the Scottish Government to be around 6,000.

The BDA has been awarded funding from the Scottish Government Equalities Unit to build the capacity of the Deaf community to participate in wider developments, in particular, to engage with Independent Living activities as they develop. Six outreach workers were recruited to this project.

The Mental Health Strategy for Scotland was chosen as the first topic for consultation with BSL users, and a total of 14 meetings were organised. 183 Deaf BSL users were in attendance at open meetings in Inverness, Aberdeen, Dundee, Fife, Edinburgh, Dunbar, Borders, Dumfries, Glasgow and Lanarkshire. The majority of the consultations took place in November and December 2011. We also offered individual consultations for BSL users who were not keen to speak out in front of others in a group.

This is a summary of consultations by the Deaf community across Scotland. A number of quotes will be included to show some examples of gaps in the key challenges identified and to illustrate what further actions should be prioritised to help the Scottish Government to meet these challenges.

The most recurrent themes that BSL users identified were: the lack of Deaf awareness within mental health services; the stigma against Deaf people with mental health issues (which is stronger than that amongst hearing people); isolation amongst BSL users; and the lack of health professionals who can sign fluently.

## Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but **we want to consult on:**

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes.
- Whether there are any gaps in the key challenges identified.
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

Going through all the questions (35 questions under 14 broad outcomes) in the exact order with the Deaf community may be problematic, as doing so would break the flow of conversation. Thus, we identified six key themes to help us to formulate a full and thorough response:

1. The Scottish Government wants you to look after your mental wellbeing, to prevent you from becoming unwell. (*Question 2*)
2. If you are not well, the Scottish Government wants you to know where to go for help or how you can help yourself. (*Question 9, 10*)
3. How can we stop stigma and discrimination against people with mental health issues? (*Question 4*)
4. How can services be improved so that Deaf people can be assessed and treated quickly? (*Question 2*)
5. How can we improve support networks to help people cope, get better and recover? (*Question 6, 11, 15*)
6. How can we involve family members, carers, and professional staff in care and treatment? (*Question 19, 20*)

Some of the questions are outside the BDA's remit, so we have left some of the questions blank.

## Improvement Challenge Type 1

**We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes.** An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

**Question 1** In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes.

The BDA is delighted with the new Scottish Mental Health Service for Deaf People, which was officially launched in May 2011. The Scottish Government agreed to fund this new service, which is being hosted by NHS Lothian and commissioned through the NHS Services Division, which will be responsible for monitoring quality. See below link:

[www.nhsllothian.scot.nhs.uk/Services/A-Z/mhdeafservice](http://www.nhsllothian.scot.nhs.uk/Services/A-Z/mhdeafservice)

This service is long overdue, after years of campaigning by the Scottish Council on Deafness for the development of a national service for patients who are Deaf and have mental health problems.

However, some people are not aware of the service:

*"I did not know there was a new mental health service based in Livingston."*

*"I do not know where to go for help. Where is the help out there?"*

*"I have been to my GP, and he admitted he did not know where I could go for help as I am deaf. My daughter was with me and she knows what is out there for deaf people. She had to tell the GP about counselling services for deaf people, etc., and who to contact for further information. GPs know about hearing counsellors but nothing suitable for deaf people."*

*"There is a need for better publicity among GPs about the Scottish Mental Health Service for Deaf People based in Livingston. GPs will then know where to refer deaf patients."*

*"Placing deaf people with mental health problems in mainstream mental health facilities with hearing people will not work. The deaf person will become bored and will not recover. Deaf people need to be in an environment with other deaf people."*

*"There should be a hospital/clinic in Scotland where deaf inpatients can stay, to save us travelling down to England. It is easier for family and friends who may wish to visit. Perhaps a few units should be built around Scotland."*

*"There is not enough choice for deaf people to decide which mental health services or support they should go for. There are a huge number of places for hearing people to choose but for us, the choice is very limited."*

Another major remit of the SMHSDP is to be involved in facilitating training for local clinicians throughout Scotland. This is a major initiative, which provides basic Deaf awareness for staff working in mental health. The BDA welcomes this initiative, but more has to be done to ensure that BSL users have full access to community, inpatient mental health and wellbeing services which are currently available to their hearing peers.

## Improvement Challenge Type 2

**We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes.** Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

Question 2: In these situations, we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

*"It is estimated that up to 40% of deaf and hard of hearing people experience a mental health problem at some point in their lives – well over 3 million people – who are therefore likely to have contact with health and social services."*

(Hindley, P., Hill P., McGuigan S. and Kitson N. (1994) Psychiatric disorder in deaf and hearing impaired children & young people: a prevalence study. *Journal of Child Psychology and Psychiatry*, 55.5: 917-934.)

The BDA believes that this figure of 40% is outdated, as 70% of the people who attended the last Healthy Deaf Minds meeting in January 2012 said they had experienced mental health issues. In addition to this, 90% of those in attendance said they knew of someone who had experienced mental health issues.

The BDA is aware that the Scottish Mental Health Service for Deaf People also collects statistics to provide accurate data regarding the numbers of people who are Deaf and suffer mental health problems. It has traditionally been very difficult to obtain data about the level of need in this area.

In addition to this, we asked BSL users how services can be improved so that Deaf people can be assessed and treated quickly. Here are some responses:

*"Health professionals working in mental health need to have deaf awareness so that we can be assessed more quickly."*

*"I think it is hard for Deaf people to be assessed quickly because of communication problems. We will always need interpreters for doctors as we do not understand medical terms, even if they're written on paper."*

*"Counselling should be available if it is needed, and it should be suitable for deaf people. I know of some cases where deaf people have asked their GP for counselling or something similar, and been told by their GP that they did not have the money to refer them to specialised services for Deaf people, or for counsellors plus the cost of interpreting support. How can we help ourselves if no money is there?"*

In light of the current financial climate, there were concerns about where Deaf people can get help with their finances.

*"Money problems can also lead to mental health problems if people do not get help with their finances. I do not think there are any services suitable for deaf people with money difficulties, so where do they go?"*

*"CAB to advertise more within the Deaf community that they can help with any problems such as finances. This will lessen stress for Deaf people."*

*"There is a likely chance of benefits being cut, for example, Disability Living Allowance. This can lead to further mental distress for Deaf people. It is a lot easier for hearing people who can use the phone for advice, but what about deaf people? Where do we go for help?"*

There were some concerns about being wrongly diagnosed :

*"I am worried that doctors make decisions for us because we cannot communicate well. I may go for help with a mental health issue that is not severe, but I may look frustrated or angry due to communication problems. The doctor may assume I cannot make decisions, so may make them on my behalf."*

*"This has happened because of communication problems. I am worried if I am depressed and go to see the doctor, I would be wrongly diagnosed to having a more severe condition. This can happen if the doctor cannot communicate well with me, or understand me."*

*"I am concerned about misdiagnoses, as it has happened to me. After my fall, I was so down and was given tablets to help my depression. I did not know what they were for, as I did not care at the time. The tablets made me foggy and I acted like a zombie. I was then referred to a mental health hospital! It was during one of my more lucid periods that I saw this and started to enquire what was happening and why I was referred to the hospital. I was told I agreed to go there, but I do not remember this. I am concerned that this happened to other people who, unnecessarily, are in mental health hospitals. Miscommunication can, and does, happen. I did not have information at the time so I did not know what was going on and what my rights were."*

*"My mother went to my GP and was in there for 15-20 minutes and I never thought to ask why. I was very worried and stressed and took medication that affected me very badly. The doctor gave me propanomol, which damaged the kidneys and made me very ill. So much so that I was labelled as having mental health issues due to an adverse effect to the medication."*

*"Many health professionals do not know sign language, so when they see deaf people signing (fast and expressively) they may think their mental problems are more serious than they really are. Communication problems and barriers can lead to misdiagnosis too."*

Following an explanation about the consultation exercise, some BSL users felt there would be no action following consultation:

*"We have had many consultations over the years about improving Deaf people's lives and reducing discrimination, and yet I do not see any changes. What is the point of telling them what we think?"*

### **Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.**

**Question 3: Are there other actions we should be taking nationally to reduce self harm and suicide rates?**

Deaf Connections, a voluntary organisation in Glasgow, carried out research into the incidences of suicide in the Deaf community in 2007. They interviewed a total of 32 people, and the findings were both astonishing and frightening. For example, 50% of those interviewed said they had felt seriously suicidal at some time in their lives, particularly when they were young.

Those interviewed believed that certain groups within the Deaf community would be at even higher risk. They suggested:

- People from ethnic minority groups;
- Young people struggling with their sexual orientation;
- Mothers with unrecognised post natal depression;
- Newly deafened adults and their families;
- Fathers excluded from their children's lives.

More action should focus on groups at risk of experiencing multiple stigmas within the Deaf community, which require more work to be done. For example, Applied Suicide Intervention Skills Training; research by Deaf Connections showed that this Canadian model has made a real impact when working with Deaf people who might be thinking about suicide.

*"We know of a deaf person who tried to commit suicide and did some self-harming. We want to help, but we do not know how to help. We are afraid we would make matters worse by saying the wrong thing or doing something wrong. We need information and training about what to do to prevent people from self-harming or considering committing suicide. It is different and easier for hearing people as they can talk to these people, but for deaf people it is different and more difficult."*

*"We do not need to be trained fully in how to help people who are at risk. Just a little training would be sufficient for us to be confident in knowing what to do or not to do."*

*"Mental health training is needed for all of us to detect early mental health symptoms in other people, as people often do not recognise early signs of mental health issues in themselves. They often deny or ignore minor signs until it may be too late."*

Question 4: What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

*"The stigma of mental illness is stronger in the Deaf community than among hearing persons. Lack of awareness in the deaf community about mental health and mental illness contributes significantly to this experience. Some deaf people felt so stigmatized by their illness, they withdrew from the Deaf community"*

(Dwyer, C 1994, 'Mental health services and support networks for deaf people - are they adequate?' A project supported by the Victorian Deaf Society and the Victorian Council of Deaf People.)

There are still many myths about mental health issues and the treatment of mental illness within the Deaf community. 95% of people who attended the last Healthy Deaf Minds meeting in January 2012 felt there was mental health related stigma and discrimination within the Deaf community:

In addition to this, BSL users at our consultation meetings suggested that:

*"Everybody should have mental health awareness training so that we know what to expect and what to do with a person who has a mental health problem."*

*"We need training about how to deal with people who have mental health issues. That will help to reduce stigma and discrimination."*

*"I have been trying for years to stop. It is difficult to stop stigma because people have always labelled over the years, for example, relating to those who are disabled, gay and old."*

*"Awareness about mental health is necessary if we are to be encouraged to help people with mental health problems."*

*"We need to make it a subject we can talk about. My partner never wants to talk about things like that."*

*"There have been adverts to raise awareness about stroke, but I felt they were off-putting. Every time this advert came on, I just switched over to another channel. I don't know if adverts will help to raise awareness. All awareness raising adverts should have subtitles; some of the recent ones did not have subtitles."*

*"In GP surgeries, there are loads of posters on the walls for different illnesses, such as strokes and suchlike. There are posters about mental health with additional information in other languages, but there is nothing for deaf people who use BSL. There is no information accessible for deaf people."*

Consideration should be given to including mental health issues as part of schools' personal and social development curriculums, to help us to change attitudes and respect differences. The one theme that persisted throughout the discussions was the level of bullying in mainstream schools.

*"I believe stigma starts in school and bullying often starts there. I feel it is important that primary school pupils receive awareness training to prevent bullying later on in secondary schools."*

*"Education is the problem, as most deaf people do not understand depression."*

Some Deaf people felt it would be difficult to change attitudes because the Deaf community is very small, with many people knowing each other.

*"For me, Deaf people are too close, knowing each other too well, so I will probably not tell anyone if I have a mental health problem. Hearing people are more open about these issues. I would rather keep this to myself to stop gossip going around."*

*"We need training in how to stop attitudes within our community, between Deaf people. Training would help us to know how to deal with discriminatory attitudes and would mean we can be more prepared."*

*"I don't know of a more stigmatic/discriminatory issue, especially when you add in BSL. It is like a double whammy. Plus, there's the added, and increased, isolation in hospital."*

Some of the respondents thought self-stigma came from discrimination, with the experience of being discriminated against contributing towards stigma from ignorance, fear, and lack of information and understanding. In addition to this, Deaf people felt mental health services, families, friends and others in society need to recognise the effect that stigma and discrimination can have on the lives of Deaf people with lived experiences of mental health.

*"Encouragement and peer support services in the Deaf community will help to combat stigma. Peer services play a crucial role in building Deaf people's resilience by helping Deaf people to understand and learn from each other."*

*"Creating peer environments where common experience and respect are built."*

Facilitating discussion and learning will help challenge these high levels of stigma and discrimination which surround mental health issues within the Deaf community and lead to the breaking down of barriers to accessing support services.



Question 5: How do we build on the progress that *see me* has made in addressing stigma to address the challenges in engaging services to address discrimination?

There are still many myths about mental health issues and the treatment of mental illness within the Deaf community. Facilitating discussion and learning will challenge these high levels of stigma and discrimination which surround mental health issues within the Deaf community and lead to the breaking down of barriers to accessing support services.

*"We believe that much of the understanding of ourselves, our culture, rules for how people communicate and so forth is strongly influenced by incidental learning i.e. discussions accidentally overheard, TV and radio in the background environment, phone calls/discussions with relatives or friends."*

(Greenberg, M. (2000) Educational Interventions: Prevention and Promotion of Competence. P Hindley, & N Kitson (Eds) *Mental Health and Deafness* (p317). London: Whurr)

The above excerpt shows how Deaf people cannot access information about issues such as mental health in the way hearing individuals can. The *see me* campaign is not widely known within the Deaf community. More work needs to be done within the *see me* project and the media to promote the campaign and improve understanding and attitudes to mental ill-health.

*"Hearing people can have 'full' access to information, as they hear things and are able to read literature. Deaf people don't have full access."*

The BDA welcomes the launch of the recent Healthy Deaf Minds project, which is funded by the *see me* campaign and hosted by Deaf Action. This funding aims to establish a community group interested or involved in mental health so that they can run open meetings with the Deaf community about mental health, seek users' views on mental health issues and share information with health service providers.

Healthy Deaf Minds is based on a similar and very successful project in England, which has been running for a number of years. The project organises workshops for members of the Deaf community and those who work with them, on topics such as depression, parenting, bereavement, addiction, dementia and stress.

Question 6: What other actions should we be taking to support promotion of mental wellbeing for individuals and within communities?

It also appears that there is a huge need for support groups for Deaf people with mental health issues, or those who have had similar experiences. For example, many Deaf Asian people with hearing partners experience communication difficulties, which increases feelings of isolation, as they may have nowhere to go.

The Deaf community also acknowledged that it is important to have support from family and close friends to help recover from mental health issues. Having health professionals who understand our culture and are deaf aware would help them greatly.

*"It is important that we meet people who are going through, or have been through, similar experiences, such as meeting other people who have had a bereavement in their family and suchlike. Counselling is not the same, as the counsellor has not been through an experience I am going through, for example."*

*"Peer support groups are important. The Asian group is a great thing as it helps to prevent mental health issues and reduce isolation. The group allows us to talk about different issues which affect us. For Asians, the issue of communication barriers is exacerbated, as our parents do not speak English, we use sign language, and health workers speak English."*

*"We should have a choice of having group support or one to one consultations. This is more private. Peer support is good for sharing experiences."*

*"More Deaf BSL users working in mental health."*

*"There should be places where Deaf people can meet other Deaf people to help their recovery processes."*

*"When we cannot communicate, some of us may become aggressive. There is always a risk of having police involved if the situation continues. It is not our fault that we cannot communicate and need our hands and faces to talk."*

*"If I needed help, I would be able to demand access to services that are suitable for deaf people, but what about other deaf people who are vulnerable and may not know what is out there?"*

*"Small cards should be handed out to people with information about where to go for help or what to do, like a bank card."*

*"Create a DVD in BSL for deaf people – show us how to look after ourselves and where to go if we need support – some people can't read or write."*

*"Deaf people need to know about support groups that are available for Deaf people in Scotland – e.g. counselling with Deaf counsellors."*

*"To help us get better we need peer support from deaf people we can talk to in British Sign Language – our language."*

*"Deaf support groups could be set up so that people are visited when in hospital or care."*

There were also concerns about the lack of support for Deaf people residing in rural communities.

*"It is easier to support people who live in the central belt or in cities. I am concerned about those living in rural areas. I am not sure if technology is the way forward in offering support in rural areas; via webcams for example, because some people will not have computers."*

*"Emergencies occur in mental health and it is clearly impossible for a clinical team based in Livingston to respond to the immediate needs of someone in, for example, Dumfries and Galloway. The dilemma is how best to support these local teams and how to help staff who meet emergencies and urgent situations in a number of settings."*

*"Deaf people in Glasgow have their Deaf Club and organisations for Deaf people in Glasgow which are open every day. They can go there if they want information or to meet someone to talk about their problems (peer support), or go to one of the organisations for advice about where to go next (signposting). But here in Lanarkshire, the club is small and meets only once a week. There are no projects for Deaf people, so where do we go for help? Not all of us can go to Glasgow due to mobility problems, and also there are many elderly Deaf people who cannot travel to Glasgow for advice. There are barriers here for Deaf people in Lanarkshire."*

*"We need counsellors to come to rural areas, rather than us going to meet them in a city, like Edinburgh, because of transport and timing problems. When you are unwell, going to a place that you are not familiar with may cause extra problems."*

*"With Deaf clubs closing down and Deaf people having less opportunity to get together, people are concerned that isolation and loneliness will have a detrimental impact on their future and their health. It is hoped that the 'drop in' sessions are kept going so that at least there is some level of service offered to Deaf people."*

*"We need to have activities in the community. We can encourage deaf people with mental health problems to come to different activities, to deaf clubs, etc. It is important we continue to give them ongoing support."*

There appear to be issues around communication support at support groups and meetings, as several groups do not have funds to cover BSL/English interpreters. For example, Alcoholics Anonymous or one to one meetings with counsellors.

*"Support groups such as AA or similar, should be able to offer an interpreter when a Deaf person needs to access their service."*

**Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.**

**Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?**

It appears that there is plenty of information about mental health issues, but it does not cater specifically for Deaf people who may have English as their second language.

*"There is no information in BSL about mental health. I do not know where to go if I have a mental health problem."*

*"I think I would go to a hospital but there are always problems with sign language interpreters. They do not turn up on time. Once I had an emergency and the interpreter had not come for an hour and we ended up using my son to interpret instead"*

*"I would prefer to see health professionals who are Deaf aware and have some knowledge of Deaf issues."*

*"Literature and forms given to the patients and their families should be accessible for deaf people – e.g. in British Sign Language"*

It also appears that the Deaf community needs more information about what mental health means.

*"I do not know. Mental health means people who forget things."*

*"I think mental health means those with dementia, forgetfulness, depression and feeling low."*

*"For me, 'mental health' means being stressed, worrying too much, doing too much work. I need to know what 'mental health' really means."*

*"It can be difficult as mental health creeps on you without you realising. Other people may say something is not right with you, but you do not see this yourself and when you do, it may already be quite advanced. So I think it may be difficult to look after our own wellbeing."*

*"If we have information such as why we get depressed (i.e. triggers), we may be able to help ourselves. We need more information to help ourselves."*

*"For me, mental health means problems with the mind, spastic problems, problems with legs – walking, etc., unbalanced walking, deep depression."*

*"I feel I need more education about what mental wellbeing means."*

*"If I knew more about what mental health means I think I could have helped X more."*

*"To me, mental health means people finding it difficult to 'improve/recover', people feeling lonely, people needing attention, including medical attention and so on. With this, most people will need professional care, and will be unable to look after their own wellbeing. I accept that some may be able to look after themselves but a lot won't be."*

*"Mental health means people losing their tempers."*

*"Mental health for Deaf people starts because they cannot communicate with hearing people. Often hearing people cannot or won't change for Deaf people."*

*"For Deaf people, oppression, and not having our say, leads us to feel angry and frustrated. This needs to be sorted if we are to look after our health. Not being listened to by other people, we end up drawing back and not asking for anything, as it is much easier for us this way. This should not happen, we should have an equal say and respect."*

*"Deaf people are vulnerable, and no matter which school we go (i.e. a mainstream school or a deaf school) some of us receive continuous bullying and abuse, which then leads to a major 'blow up' after a while for some. Often we do not see our own problems or other people's problems until it is too late. The experience of abuse and bullying needs to be stopped if we are to keep good mental health."*

*"Many deaf people are now labelled as having mental health issues, but this is incorrect. It is because of how we are treated by society. Some days are good and we don't meet many barriers, but on other days, it can be bad."*

*"Mental health means people with a quick temper, health problems, depression, feeling low and not feeling confident. "*

*"Loss of temper happens because we cannot communicate with people, causing frustration to build up."*

*"No information and communication difficulties lead to stress, as we end up not knowing what to do or where to go."*

*"Lots of deaf people are bitter about their lives, not having full access to information, facilities and communication."*

Question 10: What approaches do we need to encourage people to seek help when they need to?

*"Information on mental health issues needs to be more available and accessible to deaf people, e.g. leaflets. Information is the KEY to a successful recovery."*

*"Schools should have mental health awareness in the curriculum so that we can be better prepared and more able to deal with issues."*

**Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.**

Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

The most recurrent theme that BSL users identified was the lack of health professionals who can sign fluently.

*"GPs and doctors in hospitals need Deaf, Deaf-blind and BSL awareness training. They need to understand the particular issues deaf people face with mental health."*

*"Make Deaf awareness training and learning sign language compulsory for people who are training to become doctors – put it in the curriculum."*

*"Doctors and counsellors should communicate in plain English and talk clearly. If they are not able to sign, they should be deaf aware and try to speak properly."*

*"If all health professionals could sign, sign language interpreters would not be needed. This would save us having to wait until an interpreter becomes available before we can make an appointment."*

*"Doctors should be able to communicate in British Sign Language, and then there would be no need to have a third person in the room."*

*"We need more Community Psychiatric Nurses (CPNs) who have good knowledge of Deaf people."*

*"All staff connected to health services should have BSL awareness training."*

*"I would prefer to be able to communicate directly with the doctor or counsellor without an interpreter or family member. Deaf counsellors or counsellors and doctors that are able to sign would be best."*

*"Front line staff need to be able to communicate with deaf people, preferably in sign language."*

*"Front line staff should be able to sign or at least communicate well with deaf people, as they are the first point of contact. We need to be comfortable and confident with these people."*

*"I have been to Paris where there is a hospital fully accessible to deaf patients from all over France. I know their health structure is different to ours, but out there deaf people have the choice of going to this particular hospital where staff can sign, including front line staff. It was a great experience seeing this and I want the same kind of service here. I do not see why the Government cannot fund such a service, as the mental health services in Lothian are for all people in Scotland. So it must be possible to set up a clinic or hospital that is fully accessible to deaf people."*

*"Doctors in hospitals and GPs should receive deaf awareness training. This will help doctors to understand Deaf people and have a better attitude towards us."*

*"Doctors should explain things in 'plain English', not give us explanations full of medical jargon."*

*"Doctors need to know how to communicate with Deaf people and they should learn how to sign. We prefer direct communication with our GPs."*

*"Introduce BSL as a subject in schools so future doctors are exposed to BSL from a young age."*

*"I want to see better access to medical centres - some GPs will only allow appointments to be booked over the phone, not face-to-face bookings."*

*"Professionals and hospital staff need deaf awareness training and should have a better understanding of the particular issues deaf people face with mental health."*

*"Deaf people cannot use the telephone and require a service whereby they can contact professional services, eg. GP, counsellor, Samaritans, for themselves, without having to go through a third party."*

*"I sometimes do not understand what my doctor writes on paper. I do not know medical words and terms. I have no interpreter with me when I see my doctor."*

*"NHS staff need to be trained in deaf awareness. They should know how and when to book sign language interpreters."*

*"All counsellors and staff should have BSL as this takes away the need for a third party to be present in sensitive situations and allows direct communication."*

*"I was told to get an interpreter myself when I tried to make a medical appointment. The clinic would not book one. They need training."*

In addition to this, some BSL users have concerns about using sign language interpreters, and on-line interpreting/counselling for Deaf people.

*"There is often the problem of trying to book an interpreter at short notice, so it can be difficult to be seen quickly."*

*"I have concerns about using sign language interpreters, due to confidentiality. I often feel exposed when I use interpreters, knowing they will learn of my personal problems. I would rather talk directly to health workers. I am very reluctant to use sign language interpreters so I may not be assessed quickly enough."*

*"In my case, when an interpreter was not available at short notice, my family came in to help with communicating and I did not like this."*

*"I attended weekly counselling sessions, and it was really hard for me as I had different interpreters every time. I had to talk to them before the appointment so that they knew what was involved. In the sessions, it could be quite hard discussing follow-up treatment and details, as each interpreter had not been involved in previous sessions. It would be a lot easier and better if the deaf patient could see a deaf professional without an interpreter. Also, both parties would understand the issues of the deaf culture and deaf identity."*

*"I do not want sign language interpreters to know too much about me. The Deaf community is too small and we know most of the interpreters. I have doubts they are capable of keeping total confidentiality."*

*"We had someone here the other week talking about Breathing Space, but I do not want to talk to a counsellor or ask for help on-line. I would prefer talking face-to-face."*

*"I don't want to use on line counselling for deaf people; I prefer face-to-face counselling. Many older people, including me, do not know how to use computers, so they cannot use this service."*

*"Sign language interpreters need to be trained to know medical terms and treatments before they work in the mental health field. It is important that interpreters undertake continuing professional development training to make sure they keep up to date on medical terms as well as new signs."*



*"I am wary about using sign language interpreters as I am not sure they are good at keeping confidences."*

*"I am reluctant to use sign language interpreters, as I know almost every one of them. I do not want them to know too much about me, and I am doubtful they are able to keep my personal issues in confidence. I do not book interpreters for my medical appointments, and yet interpreters have come to my appointments anyway. I found out that the hospital booked them on my behalf, and I feel there needs to be a better system to tell the staff if and when to book interpreters for deaf patients."*

*"I am aware of the NHS's purchasing procedures. They invite bids from interpreting agencies and freelancers to interpret medical appointments but there is no Deaf involvement in this process. We have no choice or say on who should be interpreting for us. It is all down to money, the NHS boards and the interpreting services. Our voice and concerns are not addressed or respected. I feel as if we are 'told' to go along with their choice."*

*"When we are depressed and on anti-depressant pills, our signing skills can go 'downhill' or become unclear. Sign language interpreters find us difficult to understand when we are not signing properly. Also, when we are down, we find it difficult to write things down for health professionals if interpreters are not present."*

*"I do not want to use sign language interpreters as this would mean having a third party in the room. I prefer talking directly to the health professional. All health professionals should be able to sign, so sign language interpreters would not be needed."*

*"We need better access to interpreters for appointments in the Borders. There is a big concern about the lack of interpreters in the Borders. Some Deaf people have had to wait for 14 hours or even a week before getting an interpreter whilst in hospital."*

*"Deaf people need to feel more confident about using interpreters, as some are worried about interpreters not being confidential."*

*"I prefer to have interpreters from England to ensure privacy for the patient. One patient said that he would feel awkward if he saw the interpreter again (after a counselling session) in the Deaf club and he would worry whether the interpreter would keep his information confidential or not."*

*"Most respondents admitted they sometimes asked family members to act as informal interpreters, particularly in rural areas."*

*"Interpreters used MUST be qualified and registered. It is not good enough to use someone who is a good signer just because this is an easier option."*

With regard to what changes are needed, some BSL users suggested that:

*"All GPs need to be aware of technical aids that can assist with communication, such as on line interpreting. Government funding should be available to allow all GP surgeries to have access to on line interpreting on their computers."*

*"Online interpreting can be good if we do not want a third person in the room."*

*"More interpreters! And training in mental health for them - the language is specialised."*

*"I would prefer to see the same worker if I went for help, as it would help me build up the confidence to speak to that person. If I saw a different person every time I went, I would not feel confident."*

**Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.**

**Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?**

One real example was given about a Deaf woman who had been admitted to hospital with mental health issues; she had no visitors or communication with any friends or family members for a period of three months.

*"The friend who eventually heard and visited was shocked that no-one had been to see her and could see from the patient's delighted response that she needed the support of friends."*

In general, it was agreed that families and friends should be included in care and treatment, but there is always the problem of communication.

*"Many of us have hearing family members and will need interpreters for communication, and if we bring deaf friends or family members, the NHS staff will need interpreters to understand us. It is not a perfect situation."*

*"It is important to ask the deaf patient what he/she wants during care and treatment. We do not want the patient to feel 'forced' to bring in people or certain friends. He may wish to proceed on his own."*

*"We all have hearing friends and family, but we know it is much easier to speak with other deaf people – i.e. deaf person to deaf person. There is more empathy and fuller communication this way."*

*"More publicity within the Deaf community about support groups that can help those who are facing stress and worry – e.g. Breathing Space, The Samaritans."*

*"Literature given to the patients and families should be accessible for deaf people – e.g. in British Sign Language."*

*"We need Deaf BSL users involved in the networks as examples to the rest of us – mentors, support workers, volunteers."*

*"I had asked friends to help but no one did. I think it is because they did not know how. I had also asked the council (social worker) to come and help, but no one came. Also communication problems stopped me from asking for help."*

*"It is important to have support from other deaf people who have had, or are going through, mental health problems – i.e. peer support. I want to be able to sign to other people about my mental health problems, in my own language."*

*"It is hard for Asian families when different languages are used; the parents may speak different languages, while sign language is used by deaf Asian people, and health professionals speak English."*

*"Family members should be provided training in how to support a family member with mental health problems. The training should enable the family to share concerns and worries."*

*"There should be more materials and literature about mental health issues, so we know how to help."*

*"It is hard for Deaf people to look after people with mental health problems in the house, as they cannot hear. For example, if someone has dementia, we would not be able to hear them getting up at night and leaving home."*

*"There is a lot of pressure for Deaf people who want to look after their family members in the house, e.g. their mother or father. They do not want to put them into a home, but it is hard at home when they cannot hear their cries for help, or if they have a fall. Many cases have arisen with people who have dementia. There should be more support and technical aids for these cases so that people with mental health issues can be looked after at home."*

*"Courses in mental health should be made available and accessible for those caring for people with mental health issues, to help them understand more and be more involved in their care and treatment."*

*"It is important to include family members in the care and treatment."*

*"Family, carers and professional staff need better awareness, attitudes and communication to help the Deaf patient."*

*"Deaf people are to be fully informed at all times and can make their own decisions – hearing family members are not to make decisions on their behalf."*

*"It is good to have everyone working together but sometimes it is better to have the groups separate. Especially if the patient has a hearing family or carer. They may take control and make decisions on behalf of the deaf person, which may not be the right care or treatment."*

*"The Deaf person should be involved in all discussions about care and treatment – not only his family members."*

*"Deaf people may have family members with mental health issues; they need full access to meetings with professionals – fully qualified interpreters. These professionals need deaf awareness training – not only for the patients' benefit but for their family members or carers too."*

**Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.**

**Question 19: How do we support families and carers to participate meaningfully in care and treatment?**

The most recurrent theme here was the lack of health professionals who are Deaf aware and who can sign frequently.

*"My son has mental health issues and was in Carrick Glen hospital. The staff had no Deaf awareness at all. My wife and I went to visit. We are both deaf and my son is not. When we arrived for visits they would talk at us and we had to ask them to write stuff down. It made us feel disempowered. I went regularly and there was an intercom system at the door. I had to press the bell for 15 minutes one day. People passed by and I tried to catch their attention and eventually I was let in. The next day I went back and was told that to see my son, I had to phone ahead so that they could book a room. How can I do that as a Deaf parent? It's important for the staff to have deaf awareness training because I had a poor experience there."*

**Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?**

*"All health professionals and police need to be trained in how to communicate with deaf people who have mental health issues."*