# Making health and social care information accessible

# SignHealth Workshop Bristol 11.02.14 (evening session) – Notes

## Introduction

Participants were welcomed to the workshop by facilitator Lynn Stewart-Taylor of SignHealth.

A brief introduction to the ‘making health and social care information accessible’ project was outlined.

Following this the 15 participants took part in discussion around their personal experiences and to offer views to shape the standard. All questions and answers were delivered directly in British Sign Language (BSL).

The questions posed were those asked in the ‘making health and social care information accessible – your views’ patient, carer and service user survey.

## Workshop 1 – your experiences

### Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?

Comments

* All participants use BSL as their preferred language and agreed that because their doctors do not sign there is often a language and cultural barrier between the doctor and his / her patients.
* A range of experiences were shared of staff not being d/Deaf aware and resulting communication issues.
* Booking an appointment can be problematic, as often the frontline staff and the d/Deaf person do not understand one another.
* On one occasion, I was unable to get through to the surgery on the telephone via Typetalk, so I had to go the GP surgery in person to book an appointment and request an interpreter.

### Do you usually get the communication support you need when you use NHS services?

Comments

* No, I am never asked or offered an interpreter.
* I know I have the right to have an interpreter booked but it is frustrating that GP receptionists seem to have no idea about the process to book an interpreter.
* It is important that d/Deaf patients are able to choose their preferred interpreting professional. For example, if a person has a serious illness, such as cancer, they will require a series of appointments and will often identify a preferred interpreter to be booked throughout to ensure continuity. There can be a problem with this if the healthcare service has a contract with a named agency meaning that one of their interpreters must be used. For the d/Deaf person having the same interpreter throughout offers a sense of confidence as the interpreter’s skillset is known and trusted. Having a different interpreter for every appointment means the d/Deaf person has to brief them every time and thus share private and personal information over again which can be emotionally distressing for the d/Deaf person.
* Having to wait for an interpreter to be booked can result in a delay in the d/Deaf patient being offered an appointment. This is okay for a routine appointment but not for an emergency. Some d/Deaf people may decide to see the doctor without interpreter, despite being uncomfortable with this.
* Even with an interpreter sometimes I am unsure of what being said. This may be because the interpreter does not have the right level of skills and so cannot use BSL effectively to communicate exactly what the doctor has said.
* When I am really ill I go to my doctor on own, because I know it is difficult to get an interpreter at short notice, and there are inevitably communication problems. Having to rely on written notes between me and the doctor means that although I come away with a prescription I do not have a full understanding of what has been said.
* If my communication needs are not met I do not feel like a valued patient.
* It seems that hospitals are increasingly using large spoken language agencies to provide interpreting services. In my experience this results in poorer provision of BSL/English interpreters, for example interpreters not arriving for appointments or lacking skills.
* The hospital is not always aware that I need an interpreter.
* Sometimes I get a BSL Interpreter. One positive experience happened when I was admitted to hospital and they had clearly labelled on my file that I was d/Deaf.
* Participants agreed that it is useful to have a note on the file (that the patient is d/Deaf). However experiences were shared of staff still calling out the patient’s name, rather than using visual means, to tell the d/Deaf person that it is time for their appointment.
* Hospitals and GP having different systems is frustrating. In my experience, you can request that your GP surgery books an interpreter, and sometimes they do this without prompting. However, hospitals seem to always communicate via letter and you have to then get in contact and hope that they can get an interpreter for the appointment time and date.
* I have to wait for an appointment with an interpreter, and I feel like I have to fight for an interpreter to be arranged, but yes an interpreter is there at all the appointments so I get signed and written information.
* In the past it seemed that GP practices were smaller and you were able to have a personal relationship with a particular doctor - so you did not need an interpreter. Now I feel that appointments are made without consideration for continuity of doctor. I think that d/Deaf people should have the right to choose their preferred doctor to facilitate communication.

### Do you usually get information in a format you can understand when you use NHS services?

Comments

* A printout is given but this is not the most appropriate way for information to be presented. I would like there to be time allowed for the GP to explain the information, as they know my medical history best and so could put everything in context, but no time is allowed for this. I also think that there should be time for the patient to ask any questions.
* If the material has already been translated during the appointment then the printed information to take home would be beneficial but as a stand-alone document it is not easy to read and understand.
* I find information produced by some health-related charities vague and not easy to read. It is very frustrating not to be able to pass written patient information onto my d/Deaf family members to read for themselves, for example about their condition and any support available. Instead I find that I have to try and explain this information to them in a way they can understand.

### Do you think there is any information you are missing out on when you use NHS services?

I miss out on some information = 6 I miss out on most information = 9

Comments

* Doctors should think about how they can communicate directly with their d/Deaf patients, as sometimes interpreters are not the answer and I still feel I miss out on information.
* I think that learning BSL should be compulsory for everyone then when a person qualifies to become a doctor they can sign with their d/Deaf patients.
* I miss out on most of the information in hospital and GP surgeries. All medical professionals should have some level of signing, plus a working knowledge of the domain specific BSL vocabulary and jargon.
* I had an experience where the information given in BSL by the interpreter during the appointment was different to that in the follow up letter sent by the doctor. This was especially worrying as it was in relation to medication and I had taken the wrong dose and suffered side effects.
* Staff should have d/Deaf awareness, for example about the importance of good lighting to support lip-reading, how to communicate effectively with d/Deaf people, and taking the time to explain information carefully.
* I had a positive experience when a GP referred me to a different GP who had some BSL skills. This was a wonderful surprise and meant that I received direct support from the doctor. However, I also realised how much information I had missed out on in previous visits to the GP.
* It is important for medical professional to have a good attitude. Clinicians need to be open and relaxed, especially in the presence of an interpreter, and to allow extra time for appointments with d/Deaf patients to try to minimise information being missed.
* In not having BSL video clips, or an advocate, or a d/Deaf health support worker, d/Deaf patients are missing out on information.
* It is sometimes difficult to judge how much information you are missing out on. Even with an interpreter there the d/Deaf person can still miss out on information, especially contextual details.
* On one occasion I went ahead with a doctor’s appointment even though an interpreter was unavailable. Due to a huge communication error the doctor started examining my foot when that was not what I was there for.
* When I was referred to a specialist I was told there was no funding available for an interpreter. This meant that I had no help and missed out on a lot of information.
* I would like to attend a weight loss programme, but I am unable to access the service. I worry that there would be the same issues [of being unable to contact a support service] if I was a victim of domestic violence or rape.
* There seems to be variation in the provision of interpreters. For example, for mental health services such as counselling it seems to be accepted that an interpreter is needed. But when I was referred to treatment for my bad back, no interpreter was provided and I was told it was too expensive due to the number of sessions. This meant that I could not access this service.
* In terms of cancer support, there is lots of support out there for hearing people but these are not immediately accessible for d/Deaf people.
* In my experience it is difficult for families to access specialist care, for example if the parents are hearing but there are d/Deaf children in the family.
* When someone has a terminal illness, services should think about bereavement counselling and support for d/Deaf family members. In my experience, there does not seem to be any interpreting support for this.

### Do you usually get the communication support you need when you use social care services?

Comments

* A while ago, I asked to see a social worker but no BSL interpreter was provided. This resulted in a number of problems for a family member, including the wrong equipment being provided upon discharge home from hospital. In addition, no communication support was booked for occupational therapy visits.
* Social workers should have sign language skills.

### Do you usually get information in a format you can understand when you use social care services?

Not very often = 15

### Do you think there is any information you are missing out on when you use social care services?

I miss out on all the information = 15

Comments

* Numerous examples were shared by participants of experiences when they had missed out on information from social services and / or had been unable to communicate with hearing members of staff.
* Difficulties experienced with the personal budget and assessment system were shared, including communication issues which resulted in a lack of understanding of the process and what the problem was.
* It is difficult to answer this question as it is too generic.
* During a very sensitive time for me, a lack of specialist social workers led to a month of not understanding.
* I was not able to make an informed decision about my parents’ care because no interpreter was available to translate home-care information. This made me feel disempowered.

### If health and social care organisations always gave you information in a format you could understand and if you always got the support you needed to communicate, what difference would this make to you?

Comments

* With the right information and communication support I would feel like an equal to my hearing peers.
* If a good quality interpreter was provided, I would be satisfied that I am receiving an accurate translation.
* To be able to access the complaints procedure would be empowering. I have had to write pages of English, which is stressful. The complaints procedure needs be part of the access provision and a video submission in BSL should be accepted.
* To be allocated reasonable time and feel no pressure, this in turn would be giving the interpreter time to translate in full.
* If I have the right information there will be no delay in my seeking professional help and my health problems would not worsen.
* To feel in control of my health and my health decisions - not having others to decide for me, to understand the options available to me.
* The difference would be feeling safe.
* I would only feel satisfied with direct communication, I prefer not to have an interpreter there at all as going through a third party for communication means you feel disempowered.
* To have information explained until it is understood. To have information in BSL and to be able to ask questions of doctors/nurses, whether through an interpreter or advocate.
* To have translation in BSL available, a resource library of BSL to be kept updated and current.
* They should extend NHS trust initiatives around outreach and support services, and have d/Deaf advocates.
* Most participants agreed that having an advocate or health support worker who has a high level of signing would be beneficial. Although others felt that to have an additional person in the appointment makes it feel more impersonal.

### If you have any other comments you would like to make about your experiences of getting the support you need from health and social care organisations, please tell us.

Comments

* I want to be able to have a choice about the interpreter booked for the appointment.
* I should be able to give feedback about the interpreter afterwards (and not through the same interpreter).
* We need a health charter relating to GPs, hospitals, and other professionals – to ensure the right communication and to be able to access our health information.
* The booking process for interpreters is time consuming for staff, which impacts on d/Deaf patients.
* In my view it seems like hospitals are trying to save money and so use sub-standard agencies to source interpreters.
* Advocates are important, particularly for people who have had a stroke or who have dementia, as many interpreters are not equipped to interpret for these patients.
* The NHS should agree that it is appropriate for a GP or hospital to SMS [text] a d/Deaf person to confirm booking of an interpreter, so I can relax.
* They should give d/Deaf patients a choice of interpreter, including whether they would prefer a male or female interpreter.

## Workshop 2 – getting the right information and communication support

### We think that your doctor, care worker or a receptionist at a hospital should ask everyone if they need any support. We want to write a question for them to ask, so that everyone is asked the same. What do you think about the question below?

**“Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?” Is this a good question?**

Comments

* It may be appropriate to hearing people, but something alternative should be considered for d/Deaf people.
* The question is far too long and too complicated.
* It might be better if it said, “what can we do to help you understand more?’ This would be a more positively framed question.
* There is a mutual problem in communication – it should not be seen as the d/Deaf person’s ‘problem.’
* If everyone was given a form then they could clearly select or state their communication or access needs and preferences. This is important as some d/Deaf people may not want an interpreter, they may prefer to lip read. This should also include selecting the most appropriate contact method, which might be SMS [text]. Being able to put something like 'please do not telephone me’ would be useful.

### How do you think we should ask people about their information and communication support needs?

Email = 11 Face to Face = 5 Letter = 7 Online form = 7 Text message = 9

Other = 8 [fax / video relay / text relay service (type talk) / remote interpreting (5)]

Comments

* Face-to-face would only work if there is an interpreter present or someone who can sign.

### What should organisations do to make sure that you can get communication support and information in the right format quickly?

Comments on actions which could be taken in advance

* Make NHS Direct accessible to d/Deaf people.
* Have information, leaflets, information about services and groups available in BSL.
* Have talks from people sharing their experiences interpreted. I would like to see a d/Deaf person sign information from their own experience.
* Make information available in plain English, and have an explanation or glossary for medical jargon plus a sign language version.
* Be available for face-to-face appointments. The internet is great [for accessing health information] but it is not the answer.
* Information about different illnesses and support groups should be available. Plus there should be funding so that interpreters can be booked to enable d/Deaf people to access them.
* Professionals should have better d/Deaf awareness and recognise that it is written English that is the barrier.
* Deaf people’s rights to access should be recognised and services provided.
* When doctors meet d/Deaf people, there should be sign posting to good support groups with BSL interpreters provided.

Comments on considerations in an emergency situation or late at night

* Staff working in A&E departments need to be aware of contracts in place around interpreting, and know their responsibilities to provide an interpreter.
* Try and get an interpreter straight away.
* Inform the d/Deaf patient about what is happening. If there is a staff member who can sign and is being located, let the d/Deaf person know and they can choose to wait for them or not. Do not keep the d/Deaf person waiting without being informed.
* Understand the level of sign proficiency that is required in a medical setting. Book a professional who is qualified to work and translate in that area.
* Utilise remote video interpreting as a priority option as it allows an instant service to a communication professional.
* The ambulance service should inform the hospital that a d/Deaf person is on the way, and request an interpreter.
* Ideally in-house interpreter/s would be engaged by the hospital so that the provision is already in place. A 24/7 interpreter system would be highly recommended.
* They should have interpreters on call.
* The system used to request that they telephone for an interpreter needs to be more responsive.
* There should be an app on mobile phones, to contact an interpreter as soon as possible. This could include a booking system for staff and d/Deaf patients to use.
* For life threatening illness, there should be access [to a BSL interpreter] through some form of remote interpreting service. This would at least enable you to ask initial questions and know what is happening. Otherwise you are just sat there panicking, thinking they do not know what is wrong with me.
* My mother is d/Deaf. She died in hospital. I worry that she might not have died if there had been access to an interpreter. Interpreters are more important than people give them credit for; things could be diagnosed and treated sooner.
* If the GP is referring you, they should pass that information on and explain the situation to the hospital, because they know your requirements i.e. the fact that you are d/Deaf and need an interpreter.
* For all my appointments, if I have interpreters there I am happy with information received, but when no interpreter is in attendance, or it is a last minute appointment, I will make do with written notes on paper, but I am not fully satisfied. A remote interpreting service would be really beneficial in this situation.

### Is there anything else that we should think about when finding out about people’s information or communication support needs?

Comments

* Patients should be able to give feedback about a communication professional. In order to improve the system it is important that patients are able to say if they are not happy to use a particular interpreter again.
* Deaf patients’ communication needs and preferences should be kept on record and this information should be passed on to wherever the d/Deaf patient is referred to. It should be flagged up to the next department and / or service.

### Is there anything else that we should think about when recording or sharing information about people’s information or communication support needs?

Comments

* There should be a flag on the system. I know people who have told the hospital and their GP that they are d/Deaf but it still does not seem to come up. There must be something wrong with the system; there must be a better way.
* The communication between the hospital and the GP is inefficient and needs to be improved with regards to patient information and communication preferences.
* When a member of staff tries to access a d/Deaf patient’s file there should be a pop up box that says the patient is d/Deaf. The staff member should have to acknowledge that they have read and understood this status before they can access the contents of the file.

## Close and next steps

The workshop closed with all participants being thanked for participating and sharing their views.

For more information and updates visit [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)