**Making health and social care information accessible**

**Feedback from workshops held on 29and 30 January 2014 with d/Deaf service users in Wandsworth**

Introduction

The first event took place on 29 January and was hosted by Wandsworth CouncilAdult Social Services Department as part of their regular Deaf Drop-In Service. 12 participants split into two groups to take part in discussion. The workshop was facilitated by Maria Barroso, Deaf Access Officer at Wandsworth Adult Social Services and Frances Newell, Patient and Public Partnerships Specialist at NHS England.

The second event took place on 30 January with Deaf residents and carers at a care home in Wandsworth. This discussion was facilitated by Maria Barroso. 15 participants shared their views.

Workshop 1 – discussion about personal experiences

1. **Thinking about when you use NHS and social care services:**

**a. Do you usually get information in a format you can understand?**

* No. My GP surgery does not provide a British Sign Language (BSL) interpreter.
* I cannot understand the instructions about my medication because as well as being d/Deaf, I cannot read very well. Many d/Deaf people do not read well.
* I do not understand leaflets or documents I receive about my health, such as reports from doctors or hospitals, as English is not my first language.
* I do not understand online health information, for example GP or hospital websites, NHS Direct or websites for dental surgeries.
* A number of participants explained that when they received leaflets, written information or reports from the NHS they are usually throw them away or ignore them as English presents a barrier and the information is not understood.
* I do not understand the information I am given about my medication or treatment.
* I do not understand information from the opticians, for example letters, reports, or medications.
* I do not understand the information I receive from the physiotherapy service, for example letters, reports, exercises or guidance. I do not understand the information about how to carry out instructions or exercises.
* A number of participants agreed that the factsheets from adult social services are not in an accessible format, and so they do not understand them. There is too much written information. Participants would like BSL DVD’s and / or websites with British Sign Language access.

**b. Do you usually get the communication support you need?**

* Participants did not feel they got the support they needed, and gave examples of upsetting episodes relating to an emergency (999) situation, and a laparoscopy where the patient was not asked about her communication needs.
* A number of participants also shared their experiences of being in a waiting room, and not being able to hear, so worrying about missing the appointment.
* In my experience, even if communication support is booked, it often lets you down – there seem to be lots of occasions when interpreters do not turn up.
* Often I am expected to lip read, or bring a family member. This is often not appropriate, for example if the issue is personal or sensitive.
* I feel that no provision is made for lip speakers, which some d/Deaf people need. Lip speakers also have problems when clinicians use masks, for example as dentists often do.
* A number of participants had experience of having to wait at least seven days for a BSL interpreter, even when they had requested an urgent appointment.
* Several participants had also had experience of attending an appointment, only to be informed on arrival that there is no BSL interpreter. It is felt that often GP and hospital staff blame the interpreting service or central administration team.
* When there is no BSL interpreter, there is a barrier to communication. This leads to loss of confidence and motivation. It is frustrating and stressful not to have equal access compared to hearing people.
* Participants agreed that in their experience reception staff normally ask the d/Deaf service user to bring a family member, friend or a relative along to the appointment. This includes for appointments at GP and dental surgeries, clinics, the health visiting service, and hospitals. No qualified BSL interpreter is provided so they feel excluded and face a communication barrier.
* I feel that I receive a poor service as they are unable to book BSL interpreters for my appointments. In my view therefore they have failed
* There are no BSL interpreters at breast feeding groups or maternity groups. I have been told that a co-worker is ‘too expensive.’ This leaves d/Deaf people feeling totally excluded and unable to engage in these services.
* A number of participants agreed that in their experience BSL interpreters are not made available at A&E – there is no interpreter provided for d/Deaf people in these situations.
* In my experience, opticians never provide BSL interpreters.
* I have found that front line staff do not ever seem to ask about, or to be aware of the need to provide, BSL interpreters.
* When I have had discussion meetings before having an operation BSL interpreters have not usually been provided. It seems that staff or booking teams are not aware of my communication needs. This causes additional stress which puts my health and wellbeing at risk.
* A&E is a real concern. I worry that I might need an operation quickly and that a BSL interpreter would not be booked – so I would not know what was going on or understand about my health condition.
* Some d/Deaf people rely on written information. In my experience staff lack awareness about this and are inpatient. This causes delay, stress and barriers.
* Some female d/Deaf participants shared their experiences of a lack of BSL interpreters during their antenatal appointments and labour. They felt that d/Deaf women can face huge communication barriers and miss out on key information.

**c. Do you think there is any information you are missing out on**?

* Yes, I am missing information on my medication, understanding my treatment and diagnosis, and being able to play an active part in taking responsibility for my health.
* Yes, the d/Deaf community are always missing out on health information. For example, scares, notifications, events or meetings relating to health such as stop smoking support, diabetes / breast-feeding / mother and baby groups, and health workshops.
* I am unsure of the role of the sensory team, for example, what equipment they have available and eligibility, how to apply, direct payments, procedures.
1. **What difference would it make to you if organisations always gave you information in a format you could understand and if you always got the support you needed to communicate?**
* If my communication needs were acknowledged, I would feel more confident in the NHS.
* It would reduce my anxiety and this would lead to a better health outcomes.
* I would have confidentiality, and not need to rely on friends or family.
* Having BSL interpreters arranged immediately or 24/7, instead of arranged in seven days, would mean that my health improves more quickly.
* If information was available online in BSL and with subtitles this would mean satisfaction and engagement.
* There should be BSL DVDs covering health topics for equal access.
* If appointments to discuss reports, procedures, medical information and outcomes were arranged with a BSL interpreter present it would mean that d/Deaf service users do not miss out on information about their health.
* It would mean satisfaction and reassurance. It would mean that I could gain full access and gain confidence. I would be more aware of my health, and have more understanding of health and wellbeing. It would mean inclusion and being equal to other members of society.
* In my view, staff working in GP practices, hospitals, clinics, dental surgeries, opticians and other frontline staff such as health visitors need continuous d/Deaf awareness training – to enable equal access. This would improve confidence and independence, and lead to a better quality of life all round.
* There should be a remote interpreting service available at one of the local health or community centres. This would mean that d/Deaf service users could go to the centre and use this system to ask any questions relating to health or raise a concern or complaint. The result would be full access to information and equality with hearing people. This would lead to fulfilment, assurance, confidence and independence. It would mean d/Deaf people could take control of their own lives.
* When booking appointments via the NHS Choose and Book system there should be a way of booking a BSL interpreter for your appointment at the same time. This would give d/Deaf people equal access and more control, independence and confidence.
* There should be one standard texting system established across all NHS services including GP and dental practices, hospitals, community services and opticians. This would enable equal access for d/Deaf people. It would give d/Deaf people the opportunity to learn and take control of their own health care, leading to increased confidence and independence.
* There should be a remote / video interpreting access established at clinics. This would achieve satisfaction, and provide confidence for d/Deaf service users and confidence in the NHS.

Workshop 2 – discussion about improvements

1. **How should organisations find out about your information or communication support needs?**
* A number of participants agreed that they would like to have a passport (like those which people with learning disabilities have) that includes their communication support needs and other key health information. This would mean that they do not have to repeat themselves, and it could be used in an emergency situation.
* Other participants suggested a medical ID bracelet or necklace for emergency situations.
* They should consult d/Deaf people / d/Deaf professionals and specialists continuously.
1. **What questions should they ask?**
* They should ask if a patient is d/Deaf, and if they are, whether they need a lip speaker, a note taker (palantypist), a BSL interpreter.
* They should also ensure that information recorded about your communication needs is available on the system, together with your records.
* They should ask if I would like my records printed, so I can read it and understand my diagnosis, my medication, my treatment. But they should remember that for some d/Deaf patients, written information will not work.
* They should ask, ‘Do you need BSL interpreters or other communication professionals booked for your medical appointments?’
* Participants discussed whether an NHS card, indicating that are registered d/Deaf and need communication support, for example a BSL interpreter, d/Deaf relay, lip speaker, or international sign language, would be of benefit.
* I think that ‘Deaf/BSL’ service users should be highlighted on the booking system – it should state that the service user is d/Deaf and needs a BSL interpreter (or lip speaker, or other) and it should include a link to click on for guidance on how to book a BSL interpreter, lip speaker or other communication support.
1. **What should organisations do to make sure that you get communication support and information in the right format quickly?**
* It should be highlighted in referrals and a BSL interpreter (or other support as identified) should be booked automatically. We should not have to keep chasing and worrying about whether they will actually appear.
* When an interpreter is booked, this should be confirmed to the patient, and the reference number provided, so they can follow up if there is a problem (as in my experience there often is).
* More time should be allowed for appointments for d/Deaf people, as it can take longer for us to understand and absorb information.
* GPs could make more use of visual information and video, for example showing parts of the body. This would be useful for d/Deaf people and for those who do not speak English.
* I think that there should be GPs that specialise in disabilities, who can sign and have a level of d/Deaf awareness and empathy.
* There should be more use of text messaging and email for appointments and reminders. I also think that live chat should be explored as an accessible way to connect d/Deaf people with advice and information.
* Participants agreed that organisations need a flexible range of approaches to meet the different needs of the d/Deaf community. Services need to be aware that d/Deaf people have a range of communication support needs, so one size does not fit all, and patients need to be treated as individuals – with no assumptions being made.
* I think that service users’ communication needs should be highlighted on the booking system. It should state that the service user is d/Deaf and needs a BSL interpreter (or lip speaker, or other) and it should include a link to click on for guidance on how to book a BSL interpreter, lip speaker or other. In my experience staff often say ‘I do not know how to book one’ or ‘I am not dealing with this’ or ‘I have to transfer it to the booking team’ – this duplicates work and leads to confusion and a failure to make bookings.
* I think that frontline staff should learn BSL level 1, 2, 3 to aid basic communication skills.
* I think that it is really important that d/Deaf BSL users have a qualified BSL interpreter for all appointments – not friends, family, relatives, carers or support workers.
* There could be an NHS card which service users could show to any front line staff, such as health visitors, GPs, dentists or opticians, which would explain that the individual is d/Deaf and needs a BSL interpreter. Communication needs should also be recorded on a standard system so that it is clear that the service user needs a BSL interpreter (or other communication support) throughout all medical appointments and follow up bookings.
* There should be a standard system in place and consistent good quality service. In my experience there seems to be a lot of variation, for example between GPs, hospitals and community services.
* I think it is really important that all interpreters are qualified and registered with the National Register of Communication Professionals working with Deaf and Deafblind people (NRCPD). This should be standard procedure.
* I would like there to be a central team responsible for booking communication professionals, for example using an approved list of BSL interpreters on a rota system.
* There should be remote BSL via video link available at various clinics and receptions.
1. **Is there anything else that we should think about when recording or sharing information about people’s information or communication support needs?**
* Directories of service information should include information about accessibility.
* All referrals and emergency services need to be designed to take into account the needs of d/Deaf people, for example 111 and 999.
* I do not think that there are any d/Deaf care homes. My concern is that this could mean that if an individual d/Deaf person goes into a care home – which is a hearing environment – they would not have access to communication or information. This would affect their wellbeing and health as well as feeling excluded due to barriers to communication.
* There is always a longer waiting time to see a doctor or nurse when you need a BSL interpreter, I seem to wait a long time.
* Guidance and instructions provided by the physiotherapy service should be more visual and d/Deaf friendly. They should be simple and basic. There should be the opportunity for the d/Deaf person to discuss the information with a BSL interpreter present, until they are satisfied that they understand it.

Close and next steps

Participants were thanked for this contribution to the engagement period. For more information and updates visit [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)