

## Health of Sensory Loss Communities Research

### Background

As part of their ongoing research, the JSNA Project Team received a detailed response from staff at the Deafness Support Network in Macclesfield. The response highlighted the need for further research into the experience of D/deaf people when accessing health services.

This initial report documented personal experience and comments from 25 D/deaf people who communicated with project staff through a BSL interpreter.

Further research was undertaken in February 2015 to include people with visual impairment and sight loss.

Sign Health, a national deaf charity, recently produced a report entitled 'SICK OF IT' in which they published findings from consultation with over 500 D/deaf people.

Based on its findings, the report asks challenging questions,

*“Generally speaking, Deaf people are as active as hearing people, eat a similar amount of vegetables, drink less alcohol and smoke far fewer cigarettes. So, why are they more likely to be overweight, twice as likely to have high blood pressure, and four times as likely to be on the verge of diabetes? Why are so many unknowingly living with health issues which can lead to heart attacks, strokes and other serious conditions?”<sup>1</sup>*



The 'SICK Of IT' findings suggest the answer is,

“...lack of information, poor communication, and unnecessary difficulties in getting to the doctor in the first place. All of that is outside the control of Deaf people themselves”.

The JSNA Consultation with the Third Sector Project research aims to determine if this is also the case within East Cheshire.

<sup>1</sup> <http://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-in-english/>

## **What does D/deaf mean?**

The term D/deaf is used throughout higher education and research to describe students who are Deaf (British Sign Language users) and deaf (who are hard of hearing but who have English as their first language and may lip-read and/or use hearing aids).

For the purpose of this document the term 'Standard English' has been used to describe the English language, spoken and written rather than 'BSL' British Sign Language.

## **Visit to Macclesfield Deafness Support Network (DSN)**

Prior to conducting the focus group with the D/deaf community at Macclesfield's DSN, the Project Team met with the Executive of Operations, the Health Coordinator, and a DSN Volunteer. They gave an insight into the key barriers the D/deaf community face, and also outlined two of their current projects, which are detailed below:

### **Life and Deaf Matters**

The DSN has been awarded a grant from the Health and Social Care Volunteering Fund to support all GP surgeries in Cheshire to become more deaf- friendly and are conducting an audit of GP Practices.

D/deaf people have told DSN staff about a variety of problems they face when trying to access their GP. In order to overcome these barriers to health DSN will be offering free audits to GP surgeries throughout Cheshire, and offering free basic D/deaf Awareness training. As a result of this audit, and once any required changes have been made, the GP surgery will be presented with a D/deaf friendly award and DSN will publicly celebrate their achievement.

### **Health Awareness aNd Deafness, HaND Project**

Following the success of the HaND project (Health Awareness aNd Deafness) that provided health information for deaf people, DSN has secured funding to expand the service this year.

As part of the project, Deaf people from across West Cheshire will benefit from ten health access awareness workshops, including a Health Provider Forum. Local service providers, including Cheshire West & Chester Council and Cheshire & Merseyside Commissioning Support Unit, will inform D/deaf people about health and wellbeing services available to them.

DSN Staff stressed,

*"There are many barriers which can prevent D/deaf people from receiving the health care they need, with communication being a key problem."*

There is no 'word of mouth' within the Deaf community so people don't tend to find out about health prevention issues as a hearing person would. And for individuals whose first language is BSL they are not able to read leaflets written in Standard English. As part of the HaND project, a breast cancer awareness session was provided. This resulted in a number of their service-users taking advantage of the screening service, and subsequently led to a diagnosis.

It would seem that this project could easily be replicated and provide benefits to the CCG areas in Cheshire East. Service-users within the D/deaf community express frustration that this service is not funded in Cheshire East

## Key Findings

- Many Primary and Secondary health services do not provide access to services in a Sensory Loss- friendly way.
- D/deaf friendly technology, for example screens with subtitles or vibrating devices, are not used in all waiting rooms. Conversely for those with sight loss the use of screens alone is not appropriate.
- There is evidence of need for mandatory Sensory Loss awareness training for staff, and where appropriate basic sign language awareness.
- The Life & Deaf Matters audits will help to improve the quality of service for D/deaf community. It has been suggested however that there is a need for ongoing monitoring, as changes in staff may impact on the quality of service in the long- term
- Anecdotal evidence suggests that interpreter services are not being fully utilised, ie not booked in advance of appointments and/or not appropriate to the personal nature of the examination.
- There does not appear to be sufficient funding ring-fenced for the cost of interpreters.
- There is evidence of relatives and/or individuals with only basic awareness skills, being asked to interpret rather than providing qualified interpreters.

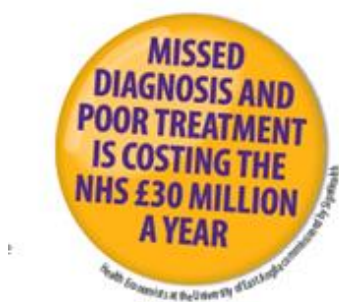
In addition to the above information gathered at the pre focus group meeting, the following points were highlighted by the staff at the Macclesfield Branch of the Deafness Support Network:

## Making Appointments

Staff at the DSN informed us that the biggest issue the D/deaf community have is the first step of actually making a GP appointment.

*"If you were to look at one of those thermometer- type charts which are used to decide which course of action to take ...often the D/Deaf person can only take the top course of action which is go A & E!"*

*“D/deaf people require the same medical provision as each and every one of us ... BUT they require the services to be accessible, that means making adjustments to the one fits all policies. For example, to make a general GP appointment you have to telephone the surgery in the morning - some D/deaf people cannot use the telephone! Others find it extremely difficult - so how do they make a GP appointment?”*  
JSNA Questionnaire response



The ‘SICK Of IT’ findings state that missed diagnosis and poor treatment is costing the NHS £30 million a year.

The staff at the DSN highlighted that often when the D/deaf individual goes for a GP or hospital appointment and there has been a failure to book and interpreter, this can lead to a visit to A&E further down the line. In fact a D/deaf person is 8 times more likely to visit A& E than a hearing person.

It has been stated that A& E departments do not record if someone is D/deaf at the first point of entry, which then makes it difficult, once they get to see a doctor, to assess their need.

It has been reported that, where A& E departments have vibrating hand -held devices to alert D/deaf patients who are waiting to be called, these are being given to people who smoke and who leave the waiting room, rather than to D/deaf people for whom they were intended.

## **Interpreters**

The staff at the DSN cited many cases, reported by their service-users, where an interpreter had not been booked for a D/deaf patient by their GP Practice. It was reported by clients that this often resulted in wasted appointments; misunderstanding regarding prescriptions, and in some cases the individual ending up at A & E. There were also examples of opposite gender interpreters being provided for intimate examinations. One Deaf lady at the focus group was so animated in sharing her experience that Project staff did not need an interpreter to understand her embarrassment.

DSN staff shared some harrowing case-studies including an individual who went into surgery not knowing they were to have their leg amputated. JSNA Project staff heard about a deaf person with a stockpile of many years’ worth of medication for high blood pressure, but as they did not read ‘Standard English’, they didn’t know what it was for. There were other stories where individuals had taken suppositories by mouth or tried to use capsules as suppositories. DSN staff support many clients by interpreting what their prescriptions are for, and how to take them.

On occasion D/deaf patients reported waiting for hours and then being recorded as a DNA (did not attend) because they were not made aware that it was their turn.

It was recognised that the cost of interpreters can be an issue. It was suggested that this should be examined against the cost to the Health Service of missed or wrong diagnosis, together with the need to provide equal access to services. It was also suggested that consideration be given to the cheaper option of annual contracts for interpreters.

The 'Sick of It' report published by Sign Health states,

*"70% of Deaf people who haven't been to their GP recently wanted to but didn't go mainly because there was no interpreter"* Sick of It <http://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-in-english/>

## Focus Group Findings

### Visual Impairment/sight loss Feb 2015

Project staff facilitated a focus group with individuals who attended Macclesfield Eye Society support groups.



The session posed the following questions

**What is happening now that works well for you when you go to see your GP or go to a hospital appointment?**

**What needs to change? How can we make it a better experience?"**

Project staff wanted to find out what provision health services made for people with sight loss who visit their GP or hospital.

The majority of individuals at the focus group were aged between 75 and 85 and generally were happy with the service provided. The older group members said they would be supported by a family member or friend to help them navigate the technology like registration screens, finding the rooms etc. More independent members of the group commented,

*"Everything being on screens can be an issue. Issues like this can make us feel cross"*

Another individual who wasn't able to use the screen to register said the receptionist was abrupt and that made her feel that she was being a nuisance.

### **Technology:**

From the small sample of individuals with sight loss surveyed, it was apparent that visits to GP and hospital required support from a sighted person.

There was nothing to indicate that increased technology could help to promote independence, rather a return to a more personal approach, like the receptionist knowing to alert the individual when it was their turn.

More independent members reported difficult registering because they could not navigate the electronic screens. No one had any experience/evidence of the availability of instructions on the screen in braille.

### **Staff and Training**

- I found my way to reception but I couldn't see a screen to register on. I was told I had to use it - I felt stupid
- I need staff to be supportive and know about the difficulties of sight-loss
- Where I go the staff know me – they're brilliant they just come and tell me when it's my turn

## **Deafness Support Network (DSN) – 3<sup>rd</sup> July 2014**

A BSL (British Sign Language) interpreter was booked for the focus group and paid for by the JSNA Project. The session started with the interpreter translating an introduction about the purpose of the focus group and about how feedback from the group would be fed into the JSNA and commissioners of services.



The session posed the following questions

**What is happening now that works well for you when you go to see your GP or go to a hospital appointment?**

**What needs to change? How can we make it a better experience?"**

Members of the focus group varied in age from early 30s to mid -70s and consisted of both males and females. The group were very open and honest in their responses and keen to share their opinions. It was crucial to have the services of the interpreter to enable face-to-face communication. The responses are summarised below and have been grouped according to the themes that emerged.

## Technology

- Booking on the internet is good.
- NHS Direct works for me, the internet chat function on NHS direct.
- Visual system when I arrive is great but this is not the case once I've checked in, and it's difficult once you're sat down.
- The internet is good.
- Have had to ask my neighbours to make me an appointment.
- If I book on the internet and don't get confirmation then I tend to walk round anyway as I don't know if it worked.
- In some surgeries there are TVs with health information on, preventative info but the subtitles are not switched on.
- We need a visual calling system or vibrating pager.

## Staff & Training

- Good facial expressions and gestures are important
- Consistency, seeing the same GP is very important and in hospital.
- The receptionist left me waiting for 2 weeks to get an appointment.
- Bad attitudes from reception – my daughter said 'why are you ignoring my mum?' – so we just walked away
- The GP ignored me and talked to my daughter
- Staff in GP's need to be D/deaf aware.
- NHS Staff are not aware of even basic signs.
- Need D/deafness awareness in GP surgeries.
- Need basic sign language for reception staff, also staff tend to forget training so this would need to be refreshed?
- Some job descriptions within the Health Services should have sign language as criteria, or mandatory training.

## Interpreters

- The GP used a pen and paper but I need an interpreter – I can't read what he wrote
- The glass is in the way, I can't use sign language through the glass or tiny speaking hole.
- Too many visual things to look at , all the leaflets are in 'Standard English'
- When they say, "Oh yes someone here can sign", and they have done a basic awareness course, not qualified, they should not be used.
- I have to take my family with me to hospital.
- Referrals must state communication needs and if a male or female interpreter is required.
- Interpreter not booked, waste of time.
- They need to check if we need a male or female interpreter.
- We need to have a good relationship with the interpreter.
- Sign is like a local dialect, basic level 1 training is not enough; we want to see the yellow badges.

- Posters in hospitals say they are available in all languages -but not BSL.
- Laws of diversity- BSL is always right at the bottom.

### **Waiting Times**

- Had to wait 2 weeks for an appointment
- Having to wait a long time.
- I waited two weeks got to the hospital
- I went to the hospital, walk in centre

### **Making Complaints**

- I tried to complain at Stepping Hill once and I had to complain to a social worker as they were the only person around who could 'sign'.
- I know lots of people who don't have the confidence to complain
- It's very difficult to make a complaint

### **Other Issues**

- My levels of deafness and communication needs are not on medical records despite being requested to do so.
- I get worried that my local doctor knows I am deaf but when I am referred on the doctors at the Heart Hospital that they won't know.
- I worry that if I was in an accident nobody would know that I am deaf
- There was a lot of campaigning in 2007/2010 but then we never saw them again it's the same every few years.
- If you are the only D/deaf child in a family your experiences can be very different from those who grow up in a D/deaf family, this is also the case for cared- for children.

## **Development of Health and Wellbeing Centre in Crewe**

The focus groups were asked what they would want to be included in the design of the new Wellbeing Centre in Crewe, specifically what would enable them to have equality of ease of access:

- Pictorial information
- Information in BSL
- Animations on a screen.
- Ramps
- Reception staff knowing some basic BSL
- Hand-held alert
- TVs with subtitles and BSL
- Internet booking
- Information/instructions in Braille
- Sensory Loss Awareness Training for reception staff and GPs



## Future Needs

The list below summarises what DSN staff & Eye Society Staff and those attending both the D/deaf focus group and Eye Society focus group are saying is needed, to provide equality of access to health services by people with sensory loss.

- *Alternative means to accessing services that don't rely on others or the telephone.*
- *Interpreters, for those who use BSL, at all appointments.*
- *Information in accessible formats.*
- *Sensory Loss Training to be mandatory for Medical staff and all front- line staff.*
- *Future planning to include provision for people with Sensory Loss*

### Recommendations

- All health services to provide equality of ease of access to appointments and consultations for those with sensory loss
- Variety of patient alerts to be used in waiting rooms, i.e. Screens with subtitles, hand-held vibrating device, and assistance from reception staff where possible
- Sensory loss awareness training to be mandatory for staff to include the procedure for accessing interpreter services
- To consider training of health staff in core 'signs'
- Fund a follow- up to the Life & Deaf Matters audits to ensure changes in staff don't impact on the quality of service to the D/deaf community.
- To consider ring-fencing funds for the cost of interpreters and/or the taking out of annual contracts with interpreters.
- That only qualified interpreters (yellow badge) should be used for interpreting, not individuals with basic awareness skills.

Louise Daniels, Jayne Cunningham, August 2014  
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This report has been read and commented on by the Deafness Support Network Macclesfield

