

Seldom Heard Voices
Visual & Hearing
Sensory Loss

Prepared by:
South Lincs Blind Society

Healthwatch Lincolnshire

Supporting 'Seldom Heard Voices'

Healthwatch Lincolnshire was formed under the Health and Social Care Act 2012 as part of the England wide Healthwatch network, to provide a safe place where everyone who uses health and care services can talk about their own experiences including what they think is good and what sometimes is not so good.

Our 'seldom heard voices' programme will provide opportunities for Lincolnshire people who don't often have a chance to speak up. This opportunity will be working with existing charities, voluntary or community groups through their members or service users.

What difference does talking to Healthwatch Lincolnshire make?

Our work is to record the health and care experiences of patients and carers and share these experiences with Hospitals, Care Homes, Day Care Services, GP Surgeries, Dentists, Pharmacists, Ambulance Services, Occupational Therapists, Community Nurses, Midwives, Mental health services in fact any government funded health or care service.

By sharing these experiences, we are helping these services to understand where things are working well and what needs to improve. These voices will really make a difference to how individuals and their families receive health and care services, now and in the future. If you want to know more about the impact of patient voices through Healthwatch Lincolnshire please ask for a copy of our impact document.

Defining Seldom Heard Voices.

To make sure Healthwatch Lincolnshire provides an equal opportunity for all Lincolnshire residents to talk to us, we have set aside a small fund to help pay for some group engagement activities. We also know that some people due to their personal circumstance can on occasions experience difficulties accessing services and again we wish to provide a small amount of funding to help these groups of people to speak up about how, where and when they access health and care services. The groups of people who we may wish to work with include some of the following:

People with mental health conditions.

People with physical disabilities.

People with learning disabilities.

People with specific illnesses.

People with sensory impairments.

Gypsy and traveller communities.

Gay, Lesbian, bi-sexual and transsexuals.

People who are homeless.

People who misuse substances.

People who live in very rural or isolated communities.

METHODOLOGY

A 10 question questionnaire was produced in consultation with Healthwatch Lincolnshire (pages 15 – 17).

This questionnaire was delivered over several weeks in 3 distinct ways to reach the conclusions within this report.

- By talking through the questions in a group discussions and within a setting familiar to those taking part.
- By telephone consultation to enable those who could not access any group meeting.
- By circulation of the written questionnaire to over 2,000 people.

As a result of these engagement practices the total of people choosing to participate in the survey was 331.

It is worthy to note at this point that the most difficult group to interact with proved to be the hard of hearing group with no written responses received at all. The groups meeting within the County are somewhat sparse and not well attended. It was pointed out to us that when dealing with people suffering severe hearing loss an interpreter was required as these people have difficulty in communicating in English as sign language is their first language. Nevertheless, it is an interesting statistic that nobody with any level of hearing loss responded by the completion of a written questionnaire.

It was also clear that by communicating with groups of people in surroundings they are familiar with produced the highest levels of debate and personal interaction as they appeared to be far more comfortable in discussing health and social care issues.

QUESTION 1

Do you feel able and confident to contact health and social care providers to make appointment bookings?

	YES	NO
Written response	56	71
Telephone	11	69
Face-to-Face	78	46
TOTAL	145	186
	43.80%	56.20%

COMMENTS

I cannot see the telephone to make calls.

I relay upon my wife to make appointments for me.

I cannot read or remember numbers.

I have problems talking to GP receptionists.

I need an interpreter at appointments due to my deafness.

As a deaf blind person it is difficult to make appointments.

I have a big problem with the attitude of healthcare receptionists.

We need to have walk in appointments at our GPs.

Self registration at a doctors or hospital using a computer touch screen is impossible for a visually impaired person.

Telephone options given out over the phone are hard to follow if you are blind.

I have to wait for my carer to do it for me.

Trying to make appointments and arrange transport is a nightmare.

I cannot write down any information given to me over the phone when making appointments.

Because I can't see I panic and stutter with unknown people making things very difficult for me.

QUESTION 2

Do you feel that service provider organisations have the right

Telephone	58	16
Written response	6	159
Face-to Face	86	6
TOTAL	150	181
	45.00%	55%

COMMENTS

No transport so more would be useful.

Regular contact with a healthcare support worker.

We do not have support at all.

Healthcare workers need to return phone calls.

Glass sliding doors, signage, self check in, A-Boards are all useless for a blind person so better communication is needed.

Low vision clinic doesn't provide or explain equipment other than a magnifier, better support is needed.

Much more empathy.

We need more of what the blind societies provide.

More accessibility for wheel chair users.

More support from social services.

More visual and deaf awareness training for professionals.

Better signage for blind people.

Interpreters for deaf people.

QUESTION 3

Do you feel that there are adequate adaptations/alterations made to the places you visit to access services with your sensory impairment?

Written response	7	158
Telephone	48	26
Face-to-Face	78	14
TOTAL	133	198
	40%	60%

COMMENTS

Audio announcing doors.

Better highlighting of steps, particularly at GP practices.

Bollards at premises should be colour coded.

Touch screens should have audio facilities.

Better lift key pads at Boston Pilgrim Hospital.

Hand dryers in toilets should be colour coded and not white.

Clearer signage.

Doctors to collect visually impaired patients from waiting rooms.

Corridors and pathways to be kept clear of clutter.

More disabled toilets.

Better sound systems in GP practices.

QUESTION 4

When you are meeting with health and social care staff such as Doctors, nurses, dentists, consultants or care workers do you feel that your needs are understood

Face-to-Face	80	7
Written response	62	111
Telephone	46	25
TOTAL	188	143
	56.80%	43.20%

COMMENTS

Training for clinical staff in visual and hearing loss awareness.

More trained sign language interpreters.

Case notes should be clearly marked with a person's disability.

Better understanding by clinical staff of the person's disability needs.

My medical needs are met, my emotional are not.

Hospital departments are oblivious to the needs of a visually impaired person other than in the eye clinics.

A better understanding by social care of the needs of a visually impaired person who may also be a carer.

Better trained receptionists. "No sight means NO brains" to many.

Longer appointment times.

Better communications.

QUESTION 5

Do you consider that the way in which service providers communicate with you recognises your sensory impairment needs?

Written response	51	122
Telephone	40	31
Face-to-Face	53	34
TOTAL	144	187
	43.50%	56.50%

COMMENTS

More visual impairment training for staff.

Better signage in doctors' surgeries.

More sharing of information about my hearing loss.

Staff to read notes and be aware of my disability.

Information transcribed into a suitable format.

To be looked at as a person and not as a disability.

More contact with social care.

More telephone calls and less letters.

Pre-booking of interpreters to coincide with my appointments.

More use of voice mail messages, text messages and e-mail.

Audible medication packaging.

Computer systems should highlight disabilities.

QUESTION 6

Do you feel that there was sufficient social and mental health support when you were diagnosed with a sensory impairment?

Written response	0	172
Telephone	43	29
Face-to-Face	67	20
TOTAL	110	221
	33.00%	67.00%

COMMENTS

There should be full time eye clinic liaison officers in our eye clinics. We should have proper emotional support. One person quoted her experience when diagnosed as being permanently blind and told "go home and learn to live with it".

When asking about sign language being told "what about it?".

There should be better mental health support. Being told, "nothing more can be done so sorry and goodbye". "We will need to take your driving licence away from you soon".

Better ongoing social support.

Doctors to be more aware of support services.

More support from nurses in eye clinics.

Job training and re-training after diagnosis.

More access to aids and equipment.

To be treated more as human beings.

An explanation of the specific conditions in layman language.

Better information at the point of diagnosis.

QUESTION 7

Do you feel that you receive or have received sufficient social support following your registration or diagnosis of sensory loss?

Written response	20	149
Telephone	55	20
Face-to-Face	74	13
TOTAL	149	182
	45.00%	55.00%

COMMENTS

More continuity of support.
Support for education.
More contact with service providers.
Home visits.
Social activity support.
Better information.
More statutory support as most is given by charities.
A return to the days of having social workers.
Better cross border information.
More large print books.
"There is no social support".
More contact on an annual basis with your consultant.
Better support for young people.
More social interaction facilities.

QUESTION 8

Do you have sufficient knowledge and confidence to complain about any poor services you have received?

Written response	132	37
Telephone	60	15
Face-to-Face	63	24
TOTAL	255	76
	77.00%	23.00%

COMMENTS

Access to complaining is difficult when you have no sight — alternative formats of information is needed.

Better support for those suffering with mental health.

More information on how to complain.

Some sort of confidence building training.

A reassurance that a complaint will be listened to and not just dismissed.

QUESTION 9

Are there any specific areas of real concern for you to obtain health and social care services as a person suffering sensory loss?

Written response	64	105
Telephone	41	34
Face-to-Face	79	8
TOTAL	184	147
	55.60%	44.40%

COMMENTS

A lack of knowledge of where to go.

A feeling that visually impaired people are fobbed off.

A need to be treated as an equal by service providers.

A supply of trained sign language interpreters.

Better communications.

A lack of training in awareness for both sight and hearing loss.

Transport services.

Social services failing in their assessment of needs criteria.

More localised services.

A better appointment system at Lincoln County Hospital.

A better understanding of the needs of a blind person and their carer.

Quicker access to occupational therapy.

QUESTION 10

What three top things would you like to see changed that would improve your quality of life as a person suffering sensory loss?

COMMENTS

Budgets for carers.

Better communications.

More social activity.

Visual impairment training for supermarket staff.

A transport system in Lincolnshire.

Health service letters in large print.

Social groups for younger people.

Allocated health workers.

Affordable day centre services.

To be treated like a human being.

Peer support.

Action against parking on pavements.

More financial support from the government.

More support for carers.

Safer pavements.

A robotic guide dog.

Better education of sensory loss for the public.

A better attitude to sight loss by the NHS.

Better lighting in public places.

For service providers to realise that because one has a sensory loss it does not necessarily affect cognitive behaviour.

More nurses.

Computer and technology training.

CONCLUSIONS

During all of the face-to-face and telephone consultations it has been made abundantly clear that those people suffering serious sight loss feel that there is far too little support or understanding of their needs.

A lack of knowledge by service providers is a key area identified as in need of specialist training especially for front line staff.

Communication for all people suffering sensory loss was found to be of great concern and it was felt that this was closely linked to the issue of having trained staff who had at least a basic understanding of the needs by this group of people.

As ever within Lincolnshire the problem with our transport infrastructure causes many individuals a lot of problems with additional problems attributed to the needs of deaf people in respect of sign language interpreters and the requirement for better co-ordination with them and appointments.

Emotional support was an area giving many reasons to feel there is a gap in our services as currently there is no provision for direct support at the point of diagnosis and there is only one organisation providing any level of emotional support within the County and this is by a Charity.

It was expressed on a number of occasions that people suffering serious sensory loss felt that too little support is given by our statutory organisations which leads to a far greater burden being placed on Charitable organisations. In respect of sight loss the short term support is felt to be inadequate and it is hoped that long term support will be given by local government and not having to rely upon Charities to do that work.

It is generally felt that people suffering with serious sensory loss try very hard to get on with life as best they can but also feel more could be done to help them have an improved quality of life.

SELDOM HEARD VOICES

First hand views and experiences of people with a sensory impairment for mainstream health and social care provision

DATE:

GROUP VISITED:

LOCATION:

Question 1

Do you feel able and confident to contact health and social care providers to make appointment bookings?

YES/NO

If NO why is that?

Question 2

Do you feel that service provider organisations have the right systems or facilities in place to support your access needs?

YES/NO

If NO what recommendations can you make to improve your day to day access?

Question 3

Do you feel that there are adequate adaptations/alterations made to the places you visit to access services with your sensory impairment?

YES/NO

If NO what changes would you like to see?

Question 4

When you are meeting with health and social care staff such as doctors, nurses, dentists, consultants or care workers do you feel that your needs are understood?

YES/NO

If NO what recommendations would you make for improving this eg specialist training for deafblind people?

Question 5

Do you consider that the way in which service providers communicate with you recognises your sensory impairment needs?

YES/NO

If NO what suggestions do you have for improving this?

Question 6

Do you feel that there was sufficient social and mental health support when you were diagnosed with a sensory impairment?

YES/NO

If NO what support would you consider should have been available?

Question 7

Do you feel that you receive or have received sufficient social support following your registration or diagnosis of sensory loss?

YES/NO

If NO what support would you have liked to have had?

Question 8

Do you have sufficient knowledge and confidence to complain about any poor services you have received?

YES/NO

If NO what do you consider is needed for you to have that knowledge and confidence?

Question 9

Are there any specific areas of real concern for you to obtain health and social care services as a person suffering sensory loss?

YES/NO

If YES what are they?

Question 10

What three top things would you like to see changed that would improve your quality of life as a person suffering sensory loss?

1)

2)

3)

**Research carried out by :
South Lincolnshire Blind Society**



Thanks are extended to:

South Lincolnshire Blind Society social activity groups

Lincoln & Lindsey Blind Society social activity groups

Spalding deaf club