healthwatch
West Sussex

Local Peoples' Experience of Services and Living with Sensory Impairment

Healthwatch West Sussex supporting engagement to inform the development of the West Sussex County Council Sensory Impairment Needs Assessment Review

June 2021

Content

Please note this report is in font size 14 so it is more accessible to the visually impaired community. If you require a larger font size this can be arranged. The summary is also available as an audio format.

Hyper-links to webpages are shown in this highlight.

Context

The Sussex Health and Care Partnership have (as of February 2021) an **Ophthalmology Transformation Programme** underway across Sussex. The aim is to *deliver recovery and restoration through transformation, a combination of efficiency and productivity, outsourcing, service redesign and digital enablers, to address* issues the NHS has identified.

The pandemic has had a negative impact on waiting times, which has over-shadowed the fact, that in Sussex ophthalmology performance[1] has been declining for West Sussex patients.

The voice and experiences of local people, detailed here following a number of surveys, focus groups and other forms of engagement will help to inform this programme. We will be emphasising the need to create a comprehensive pathway and greater collaborative working, so people living with a sensory impairment can get the right support when they need it, not just clinical interventions.

The partner organisations within the Sussex Integrated Care System (ICS), have committed to involving patients, as well as other stakeholders to implement change. The ICS organisations have a shared ambition to introduce standardised pathways, utilise technology and implement national best practice, to optimise patient outcomes and improve their experience.

We note that Low Vision Services are out of scope of the main transformation programme and believe this service is commissioned by the local authority.

Similarly, the experiences of people living with hearing impairment will be shared with our system leaders to make sure they understand what needs to change so people are supported to live well and independently.

---

[1] (https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/)

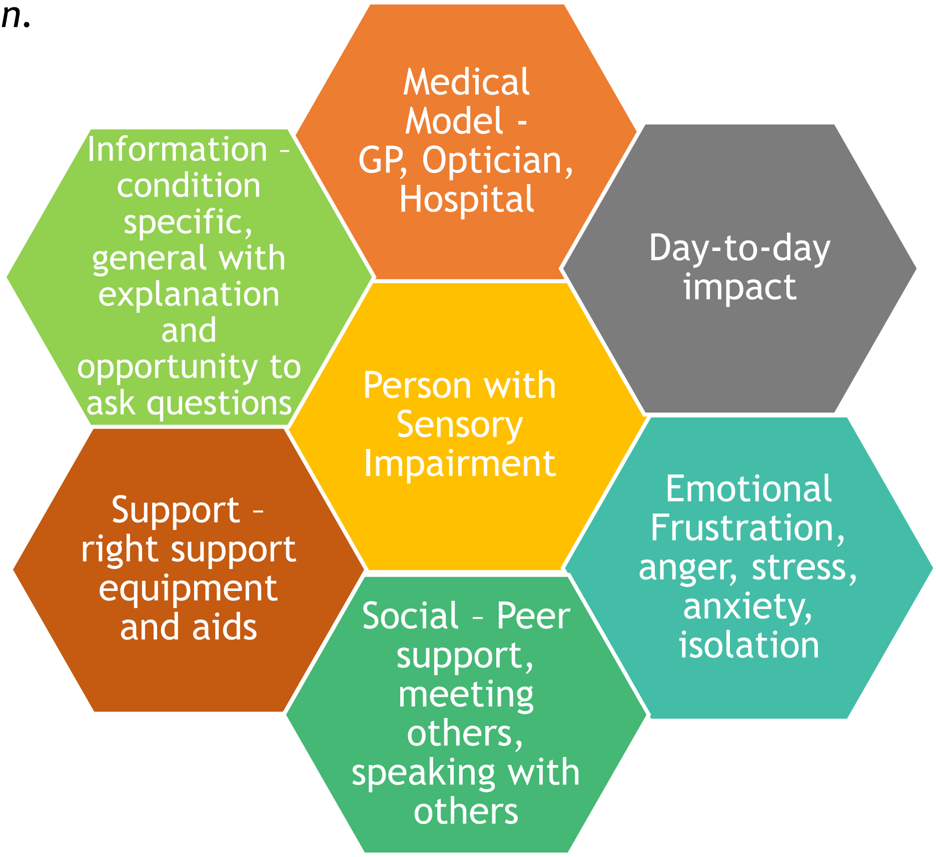
Summary

Healthwatch West Sussex, as the independent champion, in partnership with specialist community organisations, has been asking people of all ages to share their views and experiences. Similarly, we have worked in partnership with the organisations providing services and support.

A diagnosis of sensory impairment is multidimensional, individual and life changing. It impacts on a person's independence, self-confidence, self-identity, emotions, finances, social and all aspects of day-to-day living.

> My whole world had collapsed.

People see loss of vision or reduction in hearing as a sight or hearing issue and expect the health of their eyes or ears to be treated holistically – *right information, right support, at the right time, in the right place, with the right person.*



Medical Model - GP, Optician, Hospital

Information - condition specific, general with explanation and opportunity to ask questions

Day-to-day impact

Person with Sensory Impairment

Support – right support equipment and aids

Emotional Frustration, anger, stress, anxiety, isolation

Social – Peer support, meeting others, speaking with others

Our engagement with West Sussex residents finds the NHS provision in West Sussex focuses episodically (one condition at a time), so does not address issues in a holistic way. Evidence, from peoples' personal accounts, suggest that those with more than one eye condition must seek a referral per condition and wait on further appointments. While frustrating for individuals, this is likely to be more costly to deliver for our health and care agencies. Moving forward there is a need for services to look at the wellbeing of the eyes/ears in a person-centred way, to improve visual, physical, and mental outcomes.

Vision Impairment Adults

This engagement finds the Eye Health Pathway[2] to be fragmented, with the clinical elements (GP, Optician, Eye Clinic) not communicating effectively with the non-clinical elements, i.e., community organisations.

This means it is difficult to navigate the system leaving people with unmet needs, which ultimately leads to isolation and frustration. Some examples of a disjointed pathway, or as one person stated …

> “*These cul-de-sacs, need to be reduced.*”

The Eye Clinics do not always provide or explain information about the eye condition to patients or refer to the non-clinical community organisations at discharge for emotional support. One person reported *feeling brushed aside*. This may arise for a number of reasons: clinicians not having *holistic ownership*, or lack of patient involvement or simply not knowing what is available.

Whatever the reason, people are falling through the net and are not accessing the right level of support needed at the right time.

The Low Vision Service is different in each West Sussex District and can ‘*seems like a postcode lottery*’. There are Sight Care Advisors (SCA) in the south of the County and Eye Clinic Liaison Officers (ECLO) in the north of the County, but residents living in parts of Mid Sussex and Crawley are not able to access such a service. Even these services differ, as the ECLO do not follow the person through the health and care interactions, but a SCA provide a more individualised and personalised experience.

---

[2] https://www.nhsx.nhs.uk/key-tools-and-info/digital-playbooks/eye-care-digital-playbook/eye-care-pathway/

Many people spoke of the communication challenges they faced when trying to access health services. For example: IT systems not speaking to each other – leading to unnecessary and unacceptable delays and appropriate paperwork being unavailable for an appointment, follow-up appointments not communicated or cancelled.

There were also concerns in how the NHS communicates with patients:

- colour of paper used,
- font size,
- links to webpages within letters,
- and mode of communication not being suitable for visual impairment.

This was summarised by one participant, who said he just needed *timely access to information without stress and in a form that is useable*.

Communication of next steps is so important, even though there is a comprehensive pathway, next steps need to be clearly stated to ensure understanding. This is important for people to be able to make informed choices and decisions. Our insight suggests it might be **helpful for healthcare professionals to re-fresh their communication skills** for how to impart distressing news, from time to time.

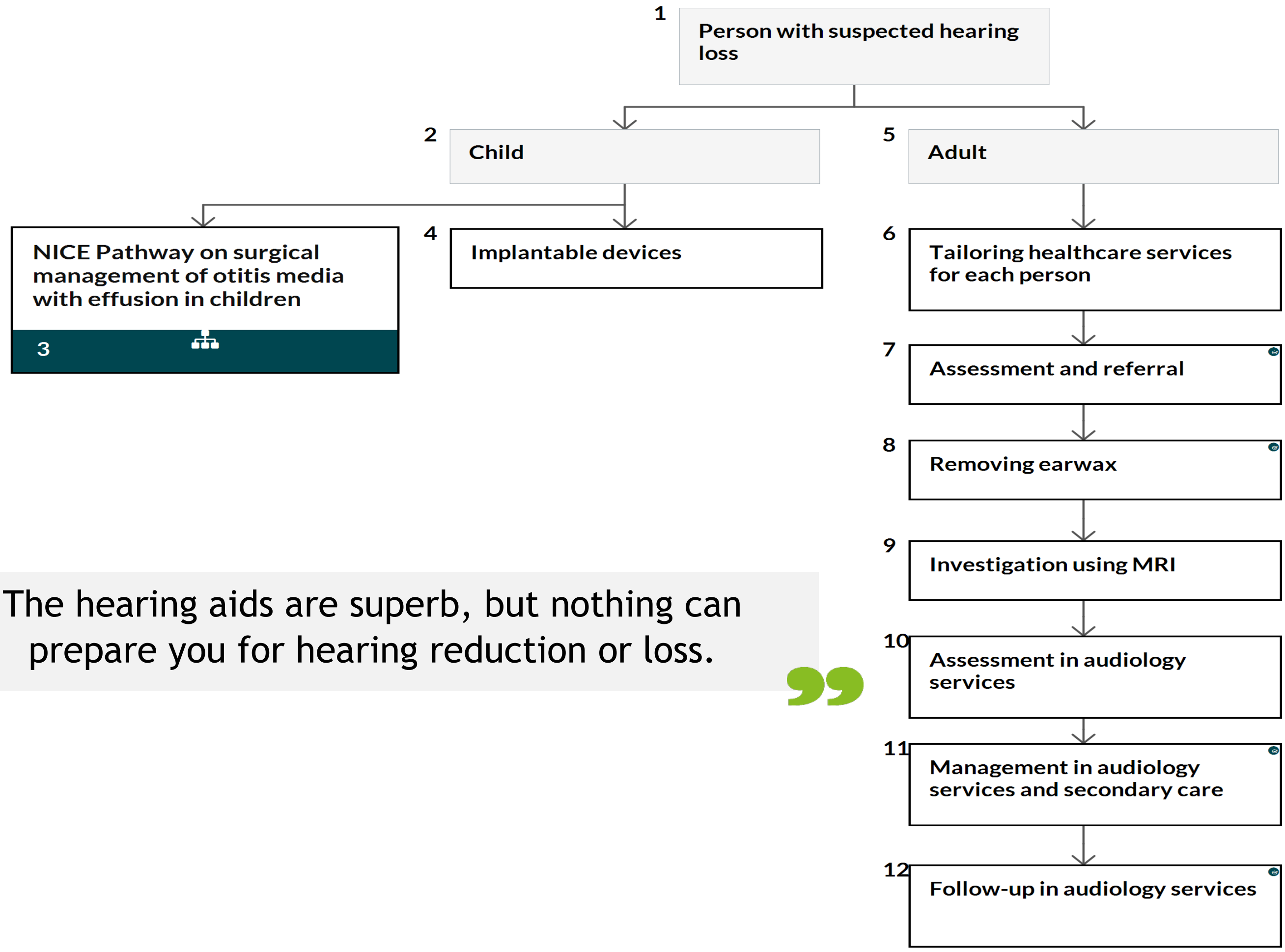
Other challenges included transport, for appointments both within the community and to medical appointments. The impact of the environment of uneven paving, street clutter, and parked cars. Other people, not understanding what the white cane represents.

Finally, the psychological effect of a visual impairment diagnosis for the person, their families, and carers is immense. Yet, despite the pathway including access to Local Authority and community experts, the Eye Clinic are not referring all patients to these areas for support (prior or at discharge).

Recognised best practice includes an integrated care model approach.

Adult Hearing Impairment

The aim of the Adult Hearing Service is to maintain hearing capabilities for adults experiencing hearing loss, with hearing aids. The White Paper, *‘Equity and Excellence: Liberating the NHS’* [3](2012), extended the choices people have over their healthcare. The goal was to enable patients to choose the provider of their services, where appropriate, from a range of Qualified Providers. It is believed, extending the choice of provider enhances quality, improves access, and addresses gaps in inequalities.



> The hearing aids are superb, but nothing can prepare you for hearing reduction or loss.

---

[3] https://www.gov.uk/government/publications/liberating-the-nhs-white-paper

Key points to note:

- Given these services are provided by Qualified Providers it is surprising to hear of the **lack of information a person receives about their hearing reduction or loss, and what happens next.**
- **Many people said they were unsure what aids/tools were available to support them** and have received little help with for their emotional wellbeing and everyday support.
- **Peer support seems to be provided from Voluntary, Community and Social Enterprise (VCSE) organisations** such as Alzheimer's Society and other condition specific organisations, where hearing loss maybe part of the condition.
- **Many specific services seemed to have closed** over the past few years, leaving behind unfilled gaps.
- **Communication accessibility was reported as a major issue for people with hearing impairment, and that lack of accessibility has made some people feel embarrassed.** For example: WSCC's pledged to follow the British Sign Language Charter. Yet the WSCC Citizen Space Consultation Hub website is considerably difficult to navigate - *not unusual for a local authority digital presence*. https://bda.org.uk/project/bsl-charter/
- **New virtual ways of working have been challenging for some, as has getting online to access services.** Some informed us that more support was needed for IT training to increase skills. Better service connections are also needed. Many people stated they prefer face-to-face conversations, as they work better with hearing aids. However, some VCSE have accessible links on their website such as Citizens Advice West Sussex. https://www.advicewestsussex.org.uk/new-bsl-live-link-connect-with-us-via-a-bsl-interpreter/
- **Physically getting to providers is challenging.** Many people expressed that they have appreciated hearing aid batteries and equipment being posted to their home address.
- **Psychosocial impact of hearing loss for a person is considerable, with feelings of being isolated and socially excluded, and feeling unsafe** – as unable to hear people from behind, other people's irritation, impact on neighbours of TV being too loud. Even those who have accessed social groups can feel isolated. More support with lip-reading, sign language and tools to support the person, carers, and families is needed.

The effect of the COVID-19 Pandemic for adults with sensory impairment

There has been a big impact on routine appointments – eye clinics, removal of ear wax, diagnostic testing, etc.

Many appointments had paused (and some remain so), leading to deterioration in people's vision/hearing.

People reported **their confidence levels have dropped**, having been *locked away for 12 months*. Many could not go out, due to their **inability to gauge social distance or the barriers this has created:** not knowing if they are two metres apart, unable to read posters on buses to know which seats are free, not able to lip-read due to face coverings.

Some people have been verbally abused because they have not followed the social distancing requirements (such as directional arrows).

> My husband lives with dementia and wouldn't remember to follow arrows.

A number of people reported feeling more isolated, with their walking having deteriorated, which added to their lack of confidence. Many shared their reluctant to re-join face-to-face groups again, even though the loss of these services has had a huge impact on them physically and mentally.

> In 22 years since diagnosis, I have never felt so isolated..

Those who have been able to access the voluntary and community services via virtual meetings have found these helpful.

In summary our engagement work shows there are gaps in the services provided and unequitable access to some service provision.

The services provided are not supporting in the round, as the limited psychosocial support occurs outside the commissioned provision/pathway and is provided by the VCSE Sector.

To ensure best outcomes, each pathway needs to embrace partnership working with the VCSE and provide full information on such provision.

Children and Young People with sensory impairment

As with the adult provision, from our engagement we found that the current service provision is fragmented, poorly co-ordinated and, poorly communicated.

The statutory services - health, education, and local authority – and voluntary and community organisations are not working together.

In the main this is a result of gaps of service provision, information, and knowledge, which can negatively affect the development and psychological wellbeing of children and young people (CYP), as well as increasing isolation and decreasing individual independence and resilience.

The pandemic stopped the regular health checks and exacerbated the inconsistent support received pre-pandemic for carers, parents and CYP. There are gaps in education support, and in the knowledge of those who support children and young people, and a lack of knowledge working with a child with special needs. **Much of the education support is currently being bridged by parents.**

Parents need the right tools to be able to support their child, it was suggested for example that BSL training is made available for families. Often children have other long-term conditions, as well as their sensory needs, which makes supporting them, from a parent perspective more challenging.

Many parents shared their uncertainty on where to go for support, as they had not received any information about which services can support so are not able to engage with these.

Some expressed real concern about whether they are best placed to support their child’s development needs, speech, independence, and day-to-day skills, as they have not been trained in these skills.

> *I contacted various charities and was told my children are not blind or disabled enough.*

A number of support organisations have closed or are now really difficult to contact, especially for hearing impairment.

Communication unsupported needs ranged from equipment – telephone, acoustic tiles, or screens, less noisier environments for conversations and using text instead of spoken word.

The COVID-19 Pandemic has made things more challenging due to the wearing of face coverings, and social distancing, which is difficult for many sensory impaired children and young people to understand or comply with.

There has been much discussion of education “catch-up” following the pandemic, this engagement highlights the importance of ensuring that the development needs of children and young people with sensory impairments and the support and advice provided to parents and carers are addressed in any local plans.

Recommendations and next steps

RECOMMENDATION

Visual Impairment Recommendations

The recommendations are made to the Sussex Health and Care Partnership Ophthalmology Transformation Programme Board and to the West Sussex County Council and its Health and Care Scrutiny Committee:

1. The promotion of non-medical services to enhance independence, self-esteem, mental health, and wellbeing should be embedded in all Eye Health Pathways and procurement specifications/commissioning contracts

2. Make sure that suitable information about the condition and associated support is provided prior to discharge, and/or when a patient is referred to community services. Then, they can be more health literate and prepared to benefit from support, which will help them to adapt to changes arising from their condition.

3. When reviewing Eye Health Pathways, the commissioning of community services is important as these can support patients' emotional, psychological, and social needs. As community services and healthcare professionals, working together ensures a holistic person-centred approach.

4. Transport to and from hospitals and hubs need to be included in the Eye Health Pathway and commissioning arrangements; as visual impairment can make driving or using public transport unsafe, and to recognise that people may need additional support.

5. Include community organisations in the transformation workshops to ensure that a wider understanding of need is captured and informs the change processes. This could include a Roundtable webinar for all professionals.

6. The Ophthalmology Programme and West Sussex Stroke Reconfiguration Teams to examine the cross over between their work, to ensure patients who have a visual stroke get prompt access to treatment and support, to achieve better health outcomes.

For all services that interface with people with visual impairment.

7. Communication and associated templates, to be offered in a range of formats to meet different patient needs. At a minimum be appropriate to an audience with reduced ability to see, standard printed material (using at a minimum font size 14, in a simple typeface such as Arial, or avoiding forwarding instructions (such as pressing phone options).

Hearing Impairment Recommendations

8. Enhance activities to achieve equality in access, for example West Sussex County Council has pledged to the British Sigh Language Charter yet the WSCC Citizen Space Consultation Hub website used for the surveys is difficult to navigate. https://bda.org.uk/project/bsl-charter/[4]

9. The impact on quality of life should not be underestimated and the promotion of non-medical services to enhance independence, self-esteem, mental health, and wellbeing should be embedded in all hearing related Pathways and procurement specifications/commissioning contracts.

10. Review Audiology Service Pathways to identify people who will always need an *annual revalidation of deafness* and those that do not as their hearing will not be regained, to recognise the resource and the emotional impact on people.

Children and Young People Recommendations

11. In line with the current Sussex Integrated Care System transformational aspirations, our statutory health and local authority, voluntary and community partners need to work together to deliver appropriate services for children and young people with sensory impairment.

12. Information in one place, that covers statutory and community support services for practical support, aids/tools, support groups and so on, that is easily accessed when searched by key words: such as visual, sight loss, hearing etc.

13. Map visual and hearing provision to identify the gaps in services for Children and Young People and their families and identify how these gaps can be met in a sustainable and appropriately personalised way.

---

[4] https://bda.org.uk/project/bsl-charter/

Introduction

West Sussex County Council is refreshing its Strategic Sensory Impairment Needs Assessment.

A **needs assessment is a way of assessing the current and future (in this case for sensory) health, care and wellbeing needs of the local community to inform decision-making**. It is important that there is a robust understanding of local need identified from residents living with or supporting someone with sensory impairment, those providing support, service providers and statutory services across West Sussex.

Healthwatch West Sussex, as the independent champion, in partnership with specialist community organisations has been asking people, of all ages, to share their views and experiences. Additionally, we have worked in partnership with the organisations providing services and support.

By engaging with people, communities, and service providers in this way, we hope to understand what is working well, what needs to change and understand where there are unmet needs. Having done this, we will seek to use this to inform future provision **so people can live safe and well with their sensory impairment**.

From the start, we knew it was important to make sure the whole of the County was covered. We achieved this through the breadth and variety of activities undertaken. We also used this as an opportunity to better understand the local impact of COVID-19 Pandemic and lockdowns on those with a sensory impairment.

The engagement has had three main parts:

1) Understanding experiences gathered through face-to-face engagement, conducted virtually due to the COVID-19 pandemic and lockdowns.
    - **4Sight Vision Support**[5] held three virtual Focus Groups with members living or supporting someone with visual impairment between December and February 2021 (25 people).
    - Healthwatch joined the **Macular Society**[1] Support Group Midhurst telecall in December 2020 (7 people).

---

[5] https://www.4sight.org.uk/

- Healthwatch joined two **Alzheimer's Society**[6], Virtual Groups in December (21 people) for people living with dementia and hearing reduction or loss and their carers.
- Two virtual Focus group sessions were planned for February for **Royal National Institute for Blind People**[7] (RNIB) members but were cancelled due to low attendance.

In all, 53 people joined these focus groups.

The focus group questions were co-designed in conjunction with people living with and/or supporting someone with sensory impairment and supported by service provider expertise. To ensure we engaged widely a story gathering sheet was distributed to those who did not wish to join a Focus Group.

2) Feedback from 130 people who completed one of four online surveys:

- Adults with hearing loss or reduction (18)
- Adults with visual impairment (77)
- Children and young people with hearing loss or reduction (22)
- Children and young people with visual impairment (13).

Each survey was available between 25 January to 21 February 2021 and accessed through the County Council's Citizen Portal, website.

The surveys were advertised through social media, through local newsletters and updates (from the County Council and VCSE).

Survey questions were designed with people living with and/or supporting someone with a sensory impairment and supported by service provider expertise.

3) Feedback from providers has been reported separately to the review lead.

Thank you to everyone who gave generously of their time to support this important piece of work.

---

[6] https://www.alzheimers.org.uk/
[7] https://www.rnib.org.uk/

Introduction to the Adult Sight Loss Pathway

The Adult UK Sight Loss Pathway[8] charts the personal journey of someone who experiences sight loss and sets out the recommended stages eye healthcare professionals (not just those within the NHS) should follow.

The pathway aim is to enhance the information that patients receive, signpost to relevant services, and ensure patients are fully supported both medically and non-medically after a diagnosis of sight loss. The pathway includes the following stages:

1. Referral
2. Diagnosis
3. Early Intervention – advice, information, emotional support
4. Registration
5. Early Intervention – reablement
6. Assessment of eligible needs
7. Social care support
8. Independent Living with full choice and control.

As part of the diagnosis stage within the pathway, patients – adults and children - may be offered a Certificate of Vision Impairment[9] depending on their condition due to being either sight impaired or severely sight impaired. This formally certifies someone as visually impaired and acts as a referral for a social care assessment and to record data to be used for research.

The certificate can trigger social services to assess needs and explore resources for aiding independence and other entitlements. In West Sussex, the sensory services team of Rehabilitation Officers for the Visually Impaired (ROVI) will visit anyone struggling with sight loss, irrespective of them having a Certificate of Vision Impairment.

Low Vision Aids and Magnifiers are essential everyday tools for those living with sight loss. The Low Vision Assessment is to ensure that a person is offered the correct level of magnification and shown how to use aids correctly

---

[8] https://www.rcophth.ac.uk
[9] https://www.rcophth.ac.uk

Conversations to understand lived experience

Living with a sight-loss – Charlotte's story (*name changed for privacy)

Charlotte* was born 25 years ago in Brighton Hospital. At one month old, she should have been transferred to Crawley Hospital, but they could not take her as she was too small. At six months she was diagnosed, and her mum was told *the oxygen levels in the incubator were too low*. As the eye specialist was on annual leave, *there was no communication that she should have been diagnosed at 11 weeks. This gap caused permanent damage*.

Every six months, an assessor would visit their home and the family had to re-live the circumstances again. They never had the same assessor twice. Charlotte is still extremely disappointed and has to ask, *how much can I trust the hospital, doctors, and nurses, if I have children?*

Charlotte does ask a lot of questions and is still asking questions. She is not bitter, just very sad that this has happened. However, it was very hard for her mum who was going through cancer treatment at the time, one reason why Charlotte was so little.

Charlotte attends appointments with the consultant alone, which can be difficult. '*he went around the houses when he told me I was going blind.*'

Since 2016, there has been nothing that can be done, as the optic nerve is damaged. Charlotte was told '*you have slipped through the net and should have been diagnosed sooner.*' Her family have found it toughest, and her gran and mum *are always fighting back the tears*. Charlotte believes that **parents need sensory impairment support** and should not be forgotten.

Charlotte finds things challenging but is very resilient, as she also lives with cerebral palsy and is a wheelchair user. Charlotte finds doctors do not listen to her. For example, *when the pressure increases the sight is lost but they didn't listen to me or trust me nor I them.* She has remaining sight in one eye, but she is **not being heard by healthcare professionals** as she needs to know everything and more about how the condition affects her.

Access is an issue. Charlotte is under an optician in Crawley, but this service cannot perform all of the tests due to the premises being on different levels, she has no transport to get there, add this to her sensory and physical issues and it is a challenge.

Visual impairment experiences – Evidence from Focus Groups

The focus group questions were co-designed with people living with and/or supporting someone with visual impairment and supported by service provider expertise. They covered the following:

- I understand my eye condition.
- I have someone to talk to.
- I can make the best use of the sight I have.
- I received the right information and support.
- I can access information making the most of the advantages that technology brings.
- How has COVID-19 pandemic impacted?

32 people joined the visual impairment focus groups. We have collated the themes from these conversations:

I understand my eye condition

Personal experience shows the Low Vision Service[10] is different in each area leaving people with a sense of it being a *postcode lottery* as to the quality and support you may receive from the service. This is supported in The RNIB Low Vision Mapping Report (2018)[11]

- In the coastal area – Southlands and St Richards Hospitals are benefitting from having access to 4Sight Vision Support, Sight Care Advisors in the eye clinics (provided by the charity for more than 20 years).
- In other areas there is the RNIB Eye Clinic Liaison Officers provide services.
- However, in parts of Mid Sussex and Crawley there are no Eye Care Liaison Officers or Sight Care Advisor service.
- In Southwick, the service is based on peoples' eligibility of sight loss.

It should be noted that many services have been paused in hospitals because of COVID-19 infection risk.

---

[10] The Low Vision Service is a statutory universal service for people with a vision impairment.

[11] https://westsussex.moderngov.co.uk/documents/s9429/Low%20Vision%20Services%20-%20RNIB%20Mapping.pdf

Julie’s story (*name changed for privacy)

Julie* was diagnosed and registered as severely sight impaired with a generic form of Macular Degeneration (Stargardt's Disease). This was 22 years ago when in early adulthood, whilst attending a private hospital in West Sussex. **On the same day Julie lost her driving licence due to this diagnosis.**

Julie engaged with the 4Sight Vision Support, Sight Care Advisors sometime after her original diagnoses. She met them at the NHS Eye Clinic.

The Advisor gave me much needed emotional support as I felt like a burden to my family, friends and I didn’t want them to feel guilty or to see me sad.

The Sight Care Advisors supported Julie with benefits, employment, and information on Access to Work as well as magnifying aids.

Julie’s main support has come from her family, her friends, and 4Sight.

People’s feedback strongly suggests the West Sussex Eye Health Pathway[12] is fragmented, with professionals services are not joined up. One person suggested “ *that these cul-de-sacs need to be reduced.* ”

The SCA and ECLO support with the registration and certification process, provide emotional support, information on accessing benefits and other services, and make referrals to the West Sussex County Council’s Rehabilitation Officers Vision Impairment (ROVI) Team and Department of Works and Pensions (DWP). They provide information about eye conditions, tools, and aids, and can offer time to provide personalised support, from *someone who understands*. The ROVI Team, register people as visually impaired. They refer to the SCA and ECLO, specialist consultants and other places.

The ROVI Team is also responsible for the care assessment and support planning for social support, visiting people at home to assess what equipment is needed to enable the person to do things safely. They may refer to Occupational Therapy for mobility support and charities such as 4Sight Vision Support and RNIB work alongside the ROVI team.

---

[12] https://www.nhsx.nhs.uk/key-tools-and-info/digital-playbooks/eye-care-digital-playbook/eye-care-pathway/

Support from Eye Clinics

Many of the participants had noticed a change in vision and either their GP or their optician had referred them to an Eye Hospital.

> “My optician in Petersfield confirmed I had dry macular, and he referred me to my GP. My GP made sure I got to Worthing Hospital’s Eye Clinic supported with gadgets.”

Yet many said they felt they had not always received the support, reassurance and the ‘Duty of Care’, they needed or would have expected from the Eye Clinics.

- I have a good understanding of my sight conditions. My Optician referred me to the Eye Clinic, but I was only able to discuss one condition at a time. So, I waited six months for a 2-minute appointment. “*This was a missed opportunity for the consultant and me.*”
- The doctors do not listen to you, and do not discuss all conditions/concerns as you may not have been referred to them for all areas.
- I referred myself to Moorfields Hospital. The consultant was brilliant for the time they were there. The consultant left, and I had one appointment afterwards and then they discharged me! They told me “*You will lose the sight and had already had two operations.*” I am now waiting for an appointment at Chichester Hospital.
- I felt ‘*brushed aside*’ by the Eye Hospital but do have an excellent optician in Burgess Hill.
- My local optician is very good, and “*they have referred me back to the Eye Clinic.*”
- It has been very difficult to get an appointment since COVID-19 “*I have been waiting five months.*”
- The consultant informed that my optic nerve was going to snap. “*This is not a humane way to tell people.*”

Communication

> When you are at the Eye Clinic you have to sit in a large waiting room, and you cannot see. The staff come out and call your name – some have foreign accents which can make it difficult to hear – and then they walk away.
>
> They disappear down a corridor and you cannot find out where they have gone. I am a gentleman with a cane, dark glasses and cannot believe they understand what it is like to live with sight loss at all.

Many participants spoke of the communication challenges they face when accessing health services.

> The consultant at Princess Royal Hospital always comes out to call you and waits for you.
>
> From a treatment point of view, they are good, but admin and staff awareness – of sensory impairment - are completely diabolical.
>
> Staff have been known to put food as far away as possible when in hospital.
>
> (This suggests a lack of understanding and ignores good practice around supporting someone who is visually impaired to navigate where food is. Similarly, not considering the proximity to a toilet, to reduce the risk of trip hazards that could be avoided if the patient is in a bed near a bathroom.)

Follow-up appointments are not always communicated, and people do not know what the next step is. Trying to gain or change appointments can be challenging.

> I received an appointment and needed to cancel this. I was on the phone for over 45 minutes and got no answer so decided to send an email. I then received 3-4 calls a day from the Worthing number and they never left a message. This could have been the automated system.
>
> Eventually, I got through and spoke with someone. I found the whole process extremely stressful.

I have someone to talk to

People suggested they tend to talk with family and friends first. *I felt unable to burden my family and friends and did not want them to feel guilty or to see me sad.*

However, there was concern of not upsetting people or understanding the longer-term implications means they would prefer to speak to others.

Some people were offered emotional support and counselling, but this wasn't always communicated or *explained as to why they needed counselling in a supportive way.*

> The last time I went to the optometrist I was asked if I wanted counselling? I was not too sure how to take this, do I need it?

Some found counselling supportive but had to wait a long time to access this. People felt they needed more *specific conversations about the medical aspects of their condition,* which universal counsellors could not provide.

The need for a more *individual approach* is required as each person at any point with any health care professional, support worker, receptionist, may be more receptive or seek knowledge and information and this should be supported. This also means that everyone engaged on the pathway can support the person, from ***referral, diagnosis, treatments to discharge***.

> Applied for counselling when I lost my job, it took nine months for RNIB counselling to start.
>
> In some places there is a cost for counselling services.
>
> I would like someone to discuss medical things with.

Getting about

Many people spoke of challenges getting to appointments and other activities.

- **You can get to *something but not back***, as the *buses do not run*.
- It is difficult to get transport for an appointment to Goring Hall from Midhurst for regular eye injections.
- We are able to get Eye Clinic appointments *but not the transport to attend*.
- Going for appointments at the clinics is restrictive due to transport issues.
- I have never driven. It is tough being reliant on friends.
- It would be so much better if you could just ring up a car/bus and they collect you.

Some participants felt the general public does not understand what the white or white and red cane represent[13], and that education/ awareness is needed – maybe something to start in schools.

Without good vision it is harder to navigate around **poorly maintained pavements.** The **'pips' at a pedestrian crossing can be too short.** Maintaining the quality of pavements and traffic lights is the responsibility of County Councils (and not district councils).

> I felt like I was taking a leap of faith when using the crossing.
>
> West Sussex County Council's Help Point was very helpful.

---

[13] https://deafblind.org.uk/deafblind-awareness-red-and-white-canes/

I can make the best use of the sight I have

Some people spoke about when they were first diagnosed receiving various pieces of useful equipment such as button telephone, red buttons for the cooker from Social Services.

> When I was first diagnosed, I was handed over to the SCA, they copied my certification and contacted the ROVI team and gave me copies of the paperwork.
>
> My whole world had collapsed – I was just sat down and told I was going blind. My journey with sight loss would have been impossible without the support of the SCA, they are absolutely essential.
>
> I have now been referred to Moorfields's Hospital and am expected not to be able to see within the next 10-15 years. I have been discharged to Rheumatology to see why. They may have to remove my left eye and as I am going blind in the right eye, they referred me to 4Sight Vision Support.

Many participants have engaged with a SCA in the Eye Clinic.

- The SCA helped with benefits, employment, and information about Access to Work as well as magnifying aids.
- The Eye Clinics provide the *medical side of things*, but the SCA provided the *practical things*.

I received the right information and support?

Information provided about the eye condition was mixed.

One participant had experienced being diagnosed and not being offered any help or support. " *My friend went to Southlands and was told she had Macular and was sent away without any information or support. I would advise anyone to get support from the Macular Society.* "

Another person suggested clinicians never give a timeframe for how quickly things might happen, and that this was important for understanding and adapting.

A lot of the participants use a white cane and have received training in how to use one from the ROVI Team. There are a lot of other gadgets available - many sight loss organisations are able to provide a catalogue of tools/gadgets:

- Hot water dispenser that measures the hot water levels.
- Talking microwave.
- Talking clocks, watches, and scales – both kitchen and bathroom.
- Scrabble and chess sets.

I can access information, making the most of the advantages that technology brings

Norman's frustrations (*name changed for privacy)

Norman* was born blind and had a career in IT. As someone who made their career in software development, he has been able to take full advantage of assistive technology, but *this is by no means a silver bullet*. One of Normans' biggest frustrations **remains the issue of getting timely access to information he needs, without stress, and in a form that can be easily digested.**

People spoke of using many aids and tools to support day-to-day living.

- Tablets and smart phones with various apps.
- Wearing specific tinted glasses for light sensitivity that have UV filters.
- Audio technology.
- Handheld magnification and imaging on laptops.
- SMART speaker (ECHO).
- Be My Eyes software.
- Brailler.
- Laptops.
- Alexa ECHO unit.
- SMART speaker.
- Use online for shopping, banking, and communication.

Some said they have equipment and devices that use Apple format and some things do not link with this. Some of the items they have purchased from RNIB have come with a CD for instructions and this has been helpful as they *can keep the CD if they need to be reminded how to use the item in the future.*

Participants said they benefited from having training in basic IT – provided by Blatchington Court[14], 4Sight Vision Support Tech Group, Access to Work and whilst attending visual impairment schools. Many shared how they had *picked things up as they have gone along and not learnt in the round.*

Accessibility issues

People expressed their irritation with **inaccessible websites -** feeling that the Equality Act should have meant sites were now accessible.

The combination of poor written format and the pandemic social distancing restrictions has made it harder for visually impaired people. As an example, people with visual impairment have had to wait for friends/neighbours to call to read letters etc.

- PDFs and emails that have links to websites. As an example, one person received a letter informing that they could book their COVID-19 vaccination and to *'press the link here'* he could not see the link.
- The TV Licence is a PDF format and Apple does not support PDF for one person all his devices are Apple, so he is unable to access information within such documents. (Suggesting a need to ask more communication and support need questions.)
- Accessibility is worse on Local Authority and NHS webpages.
- The links being in *'blue'* is an issue.

  (Bright colours are generally the easiest to see because they reflect light. Solid, bright colours, such as red, orange, and yellow are usually more visible than pastels.)
- Not being able to ask to receive information in different formats – the NHS send letters and *I have to wait for someone to visit so they can read them to me.*

---

[14] https://www.blatchingtoncourt.org.uk/

- Letters received from the Ophthalmology departments tend to be on yellow paper and have a lot of details when all I need to know is *What/When/Where* – ***keep things simple***.
- The benefits forms tend to be 40+ pages in length, these need to be accessible and easier to complete. Another example is the Blue Badge forms, which are not easy to complete.
- DWP office - you cannot access their messages. One person received a mobile message but had to contact Bognor DWP to provide the right number. He was informed that I had been set up incorrectly on the system for online and not letter, so every time he received a text message, “*I do not have enough time to write down the new number*, this increases my stress levels.”
- Arun District Council letter provides a telephone contact number, but when you phone this, you are given another number to ring.
- One person was told to write down the number on a computer, but *the number is spoken too quickly*, the system is not fit for purpose as one should not have to make workarounds.

How has COVID-19 Pandemic affected service provision?

> There does need to be someone to monitor you on a regular basis as you are not aware of the changes.

Many participants have had NHS Eye Clinic appointments and operations cancelled due to the pandemic.

- Since April (2020) I have had my routine appointment delayed by St Richards Hospital until August 2021.
- My delayed appointment went like clockwork.
- My wife and I are both visually impaired and we have missed out on our regular appointments because of COVID-19 cancellations.
- It has been difficult to chase up appointments as you have *to go to six plus places*, now I have two appointments this week.
- My optician was excellent pre-COVID-19 but now they are *not providing the field vision test*, and this is needed to maintain my driving licence.
- I had to send off my renewal for my driving licence without the field vision test and am waiting to see if it will be approved. The support I have received for this has been poor.

> My young son has found it very hard to concentrate. COVID-19 has been a huge impact on the social side – we are humans and should not be asked to be locked up at home. My son is the happiest guy, and he is getting dispirited and struggling. Just going to the shops is difficult being visually impaired as the support operations have stopped.

Many reported how hard it has been for them during the lockdowns and many stated how much their confidence levels have dropped. When using their white cane people ignore this. Some reported how the general public do not keep a distance or walk into you, so you do not want to go out.

> How do we know if you are 2 metres away from someone?
>
> I bumped my head on the screen between the cashier and me.

The Please give me space[15] visual awareness campaign has been developed by **Hidden Disabilities Sunflower** and the **RNIB**, in response to COVID-19 pandemic and the need to social distance.

Research by RNIB with a range of disability groups showed many people are finding social distancing hard and have been subjected to verbal abuse for seemingly not adhering to the guidance. The products are available as free to download signs and badges. There are a range of products to purchase.

Many have been emotionally affected.

- I can't go out because I am unable to read the posters or know which seats on the bus I can use or observe social distancing.
- I feel in a worse place now than I did when I was first diagnosed 23 years ago, if I did not have virtual meetings, it would be even more difficult.
- I have not been able to start my new business which will have to wait until we are all vaccinated.
- My daughters' world stopped; she was in college and loving it and it all stopped.
- Not being able to be the person I am and have the independence I want.

> Pre-COVID-19 I was very active – cricket, horse riding, attending Blatchington Court Over 18 social, judo and various social groups and this like others stopped.
>
> It is difficult to attend classes for example my mum is attending the gym, but I need a guide and social distancing is a challenge.

The pandemic has had a considerable impact on the physical health and condition of some - one participant stated that people with visual impairment are ***having more trips and falls than previously***.

---

[15] https://hiddendisabilitiesstore.com/shop/please-give-me-space.html

Learning from surveying adults with visual impairment

The adult visual impairment survey was completed by 77 people. Many respondents reported being diagnosed with visual impairment by the NHS/hospitals.

They were diagnosed between 1 and 10 years ago and were aged between birth to 84 years at the time of diagnoses.

62/77 respondents reported being registered sight or severely sight impaired.

Who first diagnosed your visual impairment?

Who diagnosed your visual impairment?		
1	NHS hospital	34
2	Optician	17
3	High Street SpecSavers or Boots	8
4	Your GP	3

- SpecSavers, then Worthing Hospital consultant, who was unhelpful and wrong. A private consultant referred me to Moorfields Hospital who have been amazing.

- Optician at Boots alerted my GP Surgery in January 2020 after detecting very high interocular cupping and signs of damage.

- 10 years ago, I was diagnosed with Glaucoma, my mother and grandmother were both blind. I went to SpecSavers and Boots for field tests. Both were terrible - with totally inadequate facilities. “ *I complained and they agreed the service needed more space and privacy*. The tests were in a corridor and a broom cupboard. The last time l attended no improvements had been made, this included the tests for the driving license review.

- The lady I saw was not a consultant and had to contact a consultant at Worthing Hospital, to prescribe steroids via a drip. After having steroids for three days in a row, I then saw the lady again at the eye clinic. She had the results of blood tests and the CT scan and said, “ it *was one of three things, two of which would get worse for a couple of weeks and then improve over six months and the third one was highly unlikely to be because of my age*. She wanted me to see an optic nerve specialist as soon as possible.

  Approximately 10 days later, I saw the optic nerve specialist. He looked at the scans and looked at me and said, “ you *have had a couple of strokes on the right optic nerve you will never drive again.*
  At this point he stated, “ *I can register you as partially sighted, or we could review in approximately 4 to 6 weeks*. Not knowing what to do, I jumped at the chance to have some breathing space and a review at a later date. This allowed me the chance to take in the fact that I was losing my sight.

  When I went back about five weeks later, he looked at my eyes and said, “ *I am going to register you as severely sight impaired.* As my eyes had got worse.

What were your main worries or concerns at this time?

The main worries of respondents at the time of diagnoses tended to fall into the following categories:

- Emotional,
- Social,
- Physical,
- Information provision,
- Who supported them,
- What was needed.

Many respondents shared that they **felt overwhelmed by the diagnoses and were left without appropriate support or explanation**. People questioned who can support their **emotional outcomes of depression, isolation, and increased disability.**

People were left without the **right information, awareness of treatment options and future support, which affected their acceptance of the condition, control, confidence, motivation, and self-worth.**

Some reported feeling **silenced by clinicians' tone of communication and not acknowledging their distress**.

Emotional aspects

- No timeframe made things difficult to plan.
- That I would lose sight in the other eye. Going blind.
- Not being able to work.
- Am I getting the best care?
- I'm already disabled, so it was a further blow to my independence.
- Fear of what was going to happen to me, how I'd manage to look after myself and my son.
- Confidence and panic attacks.

Social aspects

- Worried about having to give up driving.
- Difficult reading, telephone numbers, watching TV and driving.
- Concern for the future.
- Local transport issues.
- Time schedule for local buses.
- No indication of progress.
- Applied for a Blue Badge and been told *'not blind enough'*.

Physical aspects

- Understanding my environment so that I can navigate it.
- Coping as a young mum.
- How my sight would affect me.
- Light sensitivity.
- Climbing stairs at home.
- Safety when crossing the road.
- Trying to cope with everyday life.

- Total loss of sight and severe restriction on my lifestyle.
- Pavements cluttered with sandwich boards, signs and equipment for road repairs are dumped on pavements.

Peoples’ awareness of support was often accidental discovery through a different route, rather than direct information. This re-enforces unpredictable timelines require a sensitive and thorough communication network.

- Unsure of the progress of sight loss as although I was diagnosed, I still had enough vision to be able to drive but didn't know what rate I would lose my sight and although there is no cure, I was unsure where to get support.
- The thoughts that went through my head as he told me I would never drive again, “ what *if I can’t drive, I can’t work if I can’t work, I can’t pay my mortgage if I can’t pay my mortgage, I’m going to end up homeless.*
- Initially I was disgusted with the way I was told ...a booklet and that I will eventually lose my sight! As you can imagine, I was in shock and not in a good place. I was scared of everything the future had for me.
- I was told by Worthing hospital I would go blind and there was nothing they could do “ *it was brutal. I didn’t know where to turn and someone told me about 4Sight Vision Support who were wonderful.*
- I thought the operation would be successful. “ I felt *shocked* when I was told I had no sight in one eye.
- I had no diagnosis or treatment, and the GP Surgery did not recognise urgency. With backlog on NHS appointments the wait was 26 weeks or more before I could get treatment.
- How long would I be able to see? “ *Would I be able to cope with eye injections?*

Was there sufficient support in place to address these worries or concerns?

Half of respondents (n40/77) said there was **insufficient support** in place to address their initial concerns after diagnoses.

Respondents were also asked what information, specific to their sight loss they received:

Beyond your original diagnoses, have you been given any information on your sight loss?		
1	Received no information about the condition and what happened next.	36
2	Received support with various aids to help support day-to-day living.	51
3	Received no support for the emotional aspects of living with sight loss.	18
4	Received no support with day-to-day living needs.	30

The answers suggest there is a need to look at how people are supported to come to terms with their sight loss and how this impacts on their daily living.

If information received was there opportunity to have this explained?		Yes	No	Not sure
1	On your physical condition and what happens next	31	24	16
2	On visual aids available to help you with your condition	44	15	12
3	On supporting your emotional wellbeing	13	38	16
4	On supporting your day-to-day living	24	29	15

Some of those who stated there was insufficient support in place to support the social and economic impacts, explained:

- This is difficult to answer, as at first there did not appear to be any immediate support. I knew about Blind Veterans UK[16] and was ordered by a friend to join. I also later found out about '4Sight' I am now in regular contact with both organisations and know they are there to help me.
- At the time I was referred to 4Sight Vision Support by the hospital 'SCA'. She explained everything and handed me a couple of large brochures giving me contact numbers and details of places I can contact to get further information about my condition, benefits, and the process of what to do next.

---

[16] https://www.blindveterans.org.uk

- I was given the information and then left to deal with it, with my family *who* “ *I felt too guilty to talk to*. It was not till later that I got help, but it was too late to stop me from losing my job which I learnt afterwards could have been avoided.
- Blind Veterans supported me. The hospital informed Chichester Council and a ROVI came out and they were brilliant. She sorted out my computer. I have an i-pad now but am not working at present.
- No one addressed the concern as to what the *diagnosis means*, the consequence of the diagnosis, or was willing to explain they did not know how it would proceed.
- Not at first but later as I had *found work rounds for things* and this works for me. Would have liked to have met 4Sight earlier as they have many tools/aids to help maintain independence.
- Everything. No support offered at all. “ *A nurse sat with me and shook her head. She gave me the book on macular degeneration and held my hand. She was wonderful*. I was not given a follow up appointment!
- We could not get an appointment to get a diagnosis and treatment. We were “ *just batted back everywhere into a long queue with no help or advice*. In the end we had to seek help from Benenden (Hospital) Consultant was extremely alarmed and prescribed drops. He then checked me again two weeks later, but by then COVID-19 was starting to have an effect.
- It took a *very long time to find it (information) and to connect with it*. And remember you're blind.
- It was at the hospital mainly. There seemed to be “ *no plan of action* for people with sight loss after a stroke.
- *No referral* to low vision clinic.

The time span between appointments means that if anything goes wrong in the system – like a mislaid letter or appointment – this has a lengthy impact and potentially poorer outcomes. Clear communication of the next step to the patient is vital.

- “ *I fell off the radar for a year* as the letter from the optician was either *forgotten or mislaid* to my local doctor. It was a further 18 months before I walked in to see the Consultant at the hospital to be tested and diagnosed with Retinitis Pigmentosa and severely sight impaired.

How has visual impairment affected everyday life?

As with the forum conversations, survey responses mirrored much of the emotional, social, and physical loss.

Three-quarters of respondents (n58/77) believe their **sight loss has left them feeling isolated and socially excluded**. Respondents informed us that **everyday life is difficult and they are having to adapt continuously.** A number of people reported that they had lost the ability to read and write. That they need gadgets and technology to help with everyday things and **help to get these and how to use them**.

One respondent shared “ *it affects my reading, watching television, cannot see subtitles on TV, shopping, housework, clothing choice in fact all of my everyday life*. Financial and banking aspects are another area of challenge – mobile banking is difficult to access as need a *new code each time* which disappears from the mobile screen after a short time. People shared how they use tools to know where things are in their homes.

Many reported they are **nervous to leave the home** because outside is *bumpy and uncertain*. The clutter on pavements is distressing and exhausting and a barrier to going out. Others commented on the difficulty of seeing traffic when crossing the road.

“ *Not being able to watch football I do get depressed about this.*

I *trip over things easily and miss stairs*. Another shared that they knock thing over, tea pots, glasses, walk into things. “ Cars and truck wing mirrors are a serious hazard overhanging the footpath. Vehicles parked on the path are an everyday hazard. Overhanging shop frontages and old buildings that have low eaves projecting over pathways have given rise to serious head injury (in Upper Beeding). Some reported that they do not go out alone as have fallen over or misjudged the kerb and missed signs.

Communication can be really hard because you can't see people's faces, body language or expressions. It is **really difficult to talk to friends and family about sight loss.** One respondent informed that they completed this survey on an iPad in magnification.

Many reported a **huge loss of independence** due to losing their driving licence or job, not being able to secure employment and having to have others to support.

One respondent shared “ *that the loss of independence which had been built up over a period of time has deteriorated again due to COVID-19.*

Some respondents shared they have difficulties with self-care, social activities, and enrichment in life.

Many reported they live in more rural areas of the county in villages with few amenities, which has contributed to their increased loss of independence as having to *rely on others for transport*.

Shopping was highlighted as a challenge due to supermarket lighting, price labels, the coloured labels on some products on the shelves and having to ask people to read the labels. Difficulty to find what they are looking for in the supermarket and shopping generally.

Some reported how their visual impairment restricted their employment and education opportunities. One respondent wrote *‘I am now unable to work which means my life as I knew it is non-existent. I have lost all confidence; I struggle to even go out with the white stick.’* Many reported missing colleagues and meeting a wide range of people, as they have had to give up working and have become more isolated.

One respondent said it is a “ *lot of things people take for granted watching TV reading even doing buttons or poppers on baby grows, dials on all appliances, putting on make-up, bus and train times and being very careful when out*. Unable to do certain tasks safely, which includes cleaning, cooking, shopping, and personal care. Another wrote *he is reliant on his wife for transport and self-care*.

Traveling is difficult. Public transport and any aspect of travelling by road, rail or air is difficult and alarming. *One person informed that they had relied on Red Cross[17] for transport, but this was withdrawn*. One respondent shared the *benefit of Visual Impairment Assistants when travelling on trains is supportive*. People have found it difficult having lots of trips to the hospital to monitor their eyes.

The isolation of being a carer for someone with visual impairment, *not being able to go out on their own*. Carers having to introduce people, as their cared for person is unable to recognise faces. ❝ It has been devastating as totally dependent on wife who is now my carer - unpaid. *Our life has been turned upside down*. Support provided by family and friends who support with going out, holidays and transport.

Accessibility to venues *many are not accessible for my wheelchair and cannot get there on own*.

> ❝ Since being registered blind in 1986, and becoming totally blind in 1995, I have had time to adjust. The Guide Dog Association helped me to continue in my profession (teacher), and fortunately technological developments helped me to continue working (screen-reading software). I was also lucky to be supported by my family. My very gradual loss of vision has allowed me to adjust emotionally. ❞

---

[17] https://www.redcross.org.uk/

Access to community groups to help feeling less isolated or socially excluded

Just over half, (n43/77) of respondents have accessed community organisations and the main activities they provide.

Organisation

4Sight Vision Support
Blind Veterans
RNIB
Arun East U3a
Women Institute
Macular Society
Local church
Age UK
Sight Support Worthing
Local Probus
Sussex Sailability
Guide Dogs for the Blind
St. Dunstan’s

Activities

Meeting with others
Talking books
Rustington Amateur Radio Group
Telephone group/calls
Coffee mornings
Book club, theatre club, luncheon groups, days out group
History groups and quizzes
Information and explain diagnosis
Newsletter
DWP support with forms etc.
Local and national charities generally.

> I was introduced to a SCA and 4Sight when I was seen at Worthing hospital sometime after my initial diagnosis. They were the emotional outlet I needed, it was so helpful to talk to someone who understood, and I did not have to feel guilty about saying how I felt. They helped with low vision aids, advice, support, and helped to access benefits, some of which were financial to help with everyday living. They also took an interest in my social life and employment.

Confidence in communicating with others

Almost all respondents (n75/77) felt confident in communicating with others.

Stating the things that have made communication easier for them:

- Introduce yourself.
- Say the person's name so they know they are being spoken too.
- Standing still when talking.
- Be patient.
- Be in quieter environments are better than noisy ones.
- Offer to write down notes of conversation.
- Being able to see faces.

Support Services

The NHS/Hospital services and voluntary and community organisations are the main support providers for people diagnosed with a visual impairment.

Which services support you?		
1	NHS/Hospital services	59
2	Your GP	15
3	High Street Providers	26
4	Voluntary Organisations	55
5	Local Authority/Council	17
6	Other	21

As well as the voluntary and community groups detailled above other organisations who have provided support include:

- Housing Association.
- Family.
- WSCC ROVI early on.
- Glaucoma clinic at St Richards Hospital.

	Your overall experience of using support services?	1 Very Poor	2	3	4	5 Very Good
1	Quality of service	3	2	19	14	38
2	Ease of contacting the service	4	7	15	22	28
3	Ease of physically attending the service	11	7	29	11	14
4	Improvement in wellbeing from these services	5	6	19	24	19

The main issue being actually getting to the service.

Respondents were asked to confirm their preferred ways of contacting services, with telephone calls and visits in person being the most preferred option. However, for some their *family, carer or care staff made contact*, and transport was raised as a barrier for visiting in person.

	Preferred ways to be contact services?	
1	Text message	18
2	Phone call	63
3	Email	39
4	Video/Zoom	10
5	Online Chat Forum	7
6	Post a letter	14
7	Visit in person	39
8	Other	4

Further needs and support

Many of the tools listed were not used by respondents.

	Do you use the following tools and are they useful?	No	Yes	Yes not useful	No response
1	Screen reader	54	17	3	3
2	Braille keyboard	69	2	0	5
3	Voice recognition	52	21	2	2
4	Mobile app	45	27	1	4

People commented that they found other aids/tools/technology useful:

- Amazon Echo
- Tinted glasses
- White cane
- Water boiler that dispenses a set level of liquid
- Water level indicator
- Talking microwave, watch, kitchen scales, bathroom scales
- Magnifying keyboard on i-pad phone
- Long tube with bright light useful for magnification
- Light for reading
- Various magnifiers
- Smart phones and speakers
- Opti lent 6 magnifiers
- Google home hub
- Bump bonds
- E-reader to enlarge font
- Dolphin Supernova CCTV screen
- Voice recognition – Alexa
- A Guide dog.

Unsupported needs

People suggest there are many unsupported needs for those with a diagnosis of visual impairment. Stating it’s “ **difficult to know what you need when you do not know what is available**. Information received in a form when *someone cannot read*. Or are asked to attend venues which are difficult to get to as having *no transport*.

There is a need for IT training on i-pads, computer and so on. One person stated they *did not know a screen reader existed until I Googled it*.

Repeat prescriptions can be a challenge as the *blister packs of medication have to be ordered separately to the eye drops*. Another commented “ that telephoning the receptionist, *may go smoothly, or I may be told they do not normally take the order by phone*.

As with the face-to-face discussions, many reported not being advised on the positive steps they can take for their eye health and feeling isolated because of this. Some expressed that they *needed the diagnosis explained and appropriate support from their GP or healthcare professional*. Many had concerns over the long overdue *hospital check-ups and follow up appointments*. Some have been waiting for operations/ procedures for over 12 months now and their sight has deteriorated further.

Apart from visual impairment other disabilities or impairments

49 of 77 respondents live with another long-term condition or disability.

- Arthritis
- Alzheimer’s
- Fibromyalgia
- Asthma
- Atrial Fibrillation
- Depression
- Stage 4 cancer
- Immune System issues
- Rheumatology
- Hearing loss
- Diabetes
- Colitis
- Bipolar disorder
- Heart disease
- Migraine
- Osteoporosis
- Lung issues
- Prostate/urinary problems
- ME
- Just growing older
- Multiple Sclerosis
- PTDS
- COPD
- Divaterticulus

How has the COVID-19 Pandemic affected people?

There have been many changes caused by the COVID-19 pandemic and lockdowns for those living with visual impairment. Many respondents shared they struggle to understand people when wearing face coverings - as unable to *pick up on cues*. There were a number of practical challenges such as wearing a face covering and glasses as they steam up and affects peripheral vision especially walking downs stairs and for balance.

Social distancing has been an improvement for some as previously they *would have bumped into people in shops*. Many people shared that all they have done to improve their independence has been lost, communication has changed, they feel more anxious and have lost independence, which is extremely frustrating and makes people more vulnerable.

> “ *In the 22 years since diagnosis, never felt so isolated.* ”

Many support groups closed down face-to-face meetings, but some set up virtual groups – telephone befriending calls, zoom meetings - and kept in touch by newsletters. There has been a *huge impact on physical and mental health* when services closed.

Vaccine invitations were received by text but *could not see this, so had to wait for someone to visit… to read and respond for them*.

The delays to hospital appointments, regular tests and loss of direct GP services were particularly concerning and made it dangerous for some to go out due to deterioration in sight. We are *told if you have COVID-19 Stay Away, other medical things talk on phone, never come to the surgery, or expect to have a home visit*. However, some people have had appointments by telephone and virtual and found them ok.

The lack of *community transport* for appointments has been difficult to access so some have used more expensive taxis. Not being able to attend appointments on their own was a ‘*real struggle*’ as having to fight for their partner to attend with them.

Having to rely on carer or partners to navigate around and with communication is a retrograde step.

What people shared:

- I was struggling with confidence having not been out for many months there were numerous occasions where people were walking into me. This was extremely disturbing as with social distancing “*I cannot see anyone, and they do not see the white stick or do not care that the person using a white stick is unable to see them. This really scared me.*
- I have not used buses or trains since the pandemic started as extremely frightening to think about using as cannot see what I’m doing. I need assistance as I don’t know how close people are to me on the bus or where to sit.
- Had numerous hospital appointments cancelled and other appointments have been done over the telephone, which is *extremely difficult* when they are trying to do tests to find out what is happening and causing the problems with my eyes.
- Absolutely none, enjoyed immensely. Have missed meeting people. Been painting and listening to books, sitting in the garden, and the days have drifted by. Just missed physical people contact.
- Have had an online appointment which I found very challenging. Cannot see people until they are far too close to me. Always take a white stick with me, I end up in the road as even with my wife walking with me, *far too many people totally ignore us*. I no longer go for a walk at weekends as there are far too many people and not a lot of social distancing. No longer go in the supermarket with my wife, cannot see to keep my distance from people.

How have some of the COVID-19 Pandemic challenges been overcome

For some it has been by *sheer determination and stoicism*. Many stated they are keeping themselves busy, so they do not have to think about the *cancelled annual appointments, and the worrying deterioration in sight*. Many are now shopping online as they struggle with *face coverings – glasses steaming up*.

One person commented *the NHS sends out too many letters stating the same things just because I am old does not mean I am stupid.*

Isolation and loneliness were an issue as a high number informed, they have not been outside their homes since March 2020. This has meant that people feel less confident about being outside on their own *I always walk with my wife and try to keep to wide pavements so that you can get out of the way of other people*. Another added *I fear walking off under a bus*. Others have used the local shops and take short walks each day.

- Isolation is the problem, as I can no longer share time with others. I do see my daughter as she is my 'bubble'. I use the phone to keep in touch and my i-pad *'family time'*. I read on a kindle, watch rubbish on TV and do some chores and a little soft exercise.
- Support staff assist me to follow the current guidelines in relation to accessing the community and social distancing. My wife supports with Zoom calls to maintain contact with family, and grandchildren.
- Depression, anger, and frustration has increased for people during the pandemic. ❝ *Without great improvement in the NHS and Social Services administration it will continue to be an uphill battle*.

This information was shared and has some interesting videos.

Cliffs Action Plan – Winning against Age-related Macular Degeneration. https://yoolaa.co.uk/cliffs-on-line-booklet-winning-against-amd/[18] and https://www.youtube.com/watch?v=JfGlf_jlWeI[19]

---

[18] https://yoolaa.co.uk/cliffs-on-line-booklet-winning-against-amd/
[19] https://www.youtube.com/watch?v=JfGlf_jlWeI

Conversations to understand lived experience

Living with a deafness – John's story (*name changed for privacy)

John* (83 years) cares for his wife Jane* (65 years). John has cared for Jane for 38 years as she lives with a number of health conditions. Jane has been living in a Care Home and prior to COVID-19 pandemic John visited her every day.

John is deaf and doesn't get on with hearing aids and has difficulty hearing, so communication is difficult. John lives alone and relies on his friends from the Men's Group for social contact and interaction. Jane is his world.

During lockdown John became concerned he could no-longer visit Jane every day. John was feeling isolated as the Men's Group could not meet and this exacerbated his anxiety.

John was not digitally connected and didn't have a computer. His hearing loss makes telephone conversations challenging. **Carers Support West Sussex** maintained contact with John by telephone and sending letters. But he struggled to hear and communicate.

They referred John to their **Connecting Carers - Digital Champion Service** as he needed face-to-face support with his communication difficulties. He was referred to **Worthing Dementia Action Alliance** (part of Dementia Friendly Worthing), they were able to loan him a computer to see how he got on with one.

The computer was specifically prepared for John before being delivered to his home. Email and SKYPE was set up – so he could talk with Jane in her Care Home. Connecting Carers provided headphones to make it easier to join groups online. They also set aside a sum of money so he could purchase his own computer if things went well.

The service arranged for a Befriender to visit for one hour for four weeks. He assisted John with developing his computer skills and making sure he was coping at home with household chores.

John told Carers Support West Sussex that *'having a computer and someone coming in to visit him has helped enormously. He is feeling less isolated. Absolutely delighted to be able to communicate with Jane on her birthday.'*

Focusing on hearing impairment experiences

Healthwatch joined two Alzheimer's Society, Virtual Groups in December 2020 for people living with dementia and hearing reduction and their carers.

Understanding of condition

Participants shared that they had visited their GP about their hearing loss and were sent to the hospital for a test. The process took three weeks and a further couple of weeks to get the hearing aids sorted out.

> It was a social worker who noticed that my husband could not hear the questions that were being asked clearly.
>
> Hearing aids can be difficult to get used to.

Service providers

The conversation around hearing impairment seemed to fall towards service providers more than in general.

Action for Deafness[20] was founded, as a charity, in 1994 by deaf people and for deaf people in Sussex and remains a user-led organisation. They provide advice, support, information, and services to enable deaf people to lead independent lives. Adult audiology services are delivered on behalf of the NHS. A private audiology service is also available.

- Not had any problems with the service they provide for batteries which are sent through the post.
- You are able to get through by telephone for queries.
- It's just too far to travel (service being in Haywards Heath) especially on public transport.

---

[20] https://actionfordeafness.org.uk

- My GP sent me to them in Worthing, but the place looked shutdown. They did send my GP a photo and suggested we Skyped. My mobile blocked this, and my GP had to send the information on to them.
- They are great and post out batteries.
- I go for a bi-annual check-up the last one was two years ago. I will give them a call in the New Year, but goodness knows when I will get an appointment.
- My GP referred me to Action for Deafness. I have an appointment every three years, but this will be interrupted by COVID-19.
- The NHS are unhelpful and just referred me back to Action for Deafness.

Vision Express[21]/Boots[22] –both retailers who provide hearing test and aids.

- They provide an excellent service.
- My wife went to Boots for her hearing aids they were very expensive.

Loxwood Medical Practice[23]

- I get my batteries from Loxwood Surgery by prescription so am not paying for them.
- I went to Loxwood Surgery and they sent me to SpecSavers for a hearing test and they made up the prescription for the hearing aid on the spot. Really good service.
- Loxwood Surgery are excellent for all things hearing and for sight.
- My first point of call is my GP for hearing and sight issues.
- I was referred by my GP to have a hearing test.

First Community Health and Care CIC[24] is an employee-owned social enterprise, providing community healthcare services to people living in East Surrey and parts of West Sussex. First Community was created in 2011 under the Right to Request, which gave NHS staff the chance to establish social enterprises.

---

[21] https://www.visionexpress.com/
[22] https://www.boots.com/opticians
[23] https://www.loxwoodmedicalpractice.co.uk

[24] https://www.firstcommunityhealthcare.co.uk

> Attended an event at K2 (Crawley) where First Community Health were providing free hearing tests. This informed I needed a full test, which was provided at Horsham Community hospital a few weeks later.
> Excellent service.

Communication with healthcare

- I write a letter to my GP and he can pass this on to them as communication works better in a letter.
- Emails are unrealistic, as I do not have a computer.
- Adding a photograph for the new GP appointment system worked ok for us.
- Getting online is a tardy process, so I always send a letter. The old ways work best!
- Being older you do not use IT as much as younger people.
- They are unhelpful as it is difficult to communicate my needs for example telephone appointments.
- No one has explained my hearing loss to me.

The impact of the COVID-19 pandemic and lockdowns

People explained there have been more incidents of verbal abuse since lockdown. One carer stated that she has been verbally abused for not social distancing but has a problem judging spaces. *You have to do so much preparation – masks, gloves, sanitiser, remember one-way- systems.* It has all become so much more stressful.

> Going to Billingshurst shops which are small and have arrows, you get confused and overwhelmed. You follow the arrows and then you meet someone in your space. Some stores only allow three people at a time and you have to stand outside. My husband who lives with dementia would not remember to follow the arrows if on his own.

Challenges with the health system

- The GP services have been affected as the GP's have become more isolated. They tend to be following up later. *They have cut off your support*.
- The telephones and IT are a *nightmare and very frustrating*.
- It is frustrating and stressful, you phone and are told to go online.
- Not being able to get batteries through the pandemic from the NHS so have been buying them online.
- The *emotional impact of having to annually go to audiology service to* ***revalidate deafness***.

General challenges

- Virgin phones provide an awful connection. You would think *they would be good at communicating being in the industry*.
- You telephone providers and have to wait 20 minutes, now just send a letter as I cannot cope with telephones.
- The main impact is not being able to talk with people.
- My hearing makes joining a group difficult.
- The hearing aids make the conversation easier when face-to-face.

A couple of participants said their *walking has deteriorate* since lockdown began, as they have not been out the house, and this is a concern for them.

Accessibility issues

- Accessibility means those with hearing loss cannot just turn up and make an enquiry with the Council. Instead, we *need to book a signer*.
- Have been introduced to SignLive.
- I *feel embarrassed when I cannot hear people* properly.

Returning to groups post COVID-19 pandemic

People shared that they feel more cautious about re-joining groups face-to-face, even though emotionally they would like to.

Learning from surveying adults with hearing impairments

The adults living with hearing impairment survey was completed by 18 people. Many respondents reported being diagnosed with hearing loss by their GP or NHS/hospitals. They were diagnosed between 1 and 10 years ago and aged between 23 to 76 years. Only one respondent was registered as deaf.

Who first diagnosed your hearing loss?		
1	Your GP	6
2	NHS/Hospital	4
3	High Street Provider	4
4	Other	3
5	Hearing organisation	1

What were your main worries or concerns at this time?

- My main concern at this time was that I would lose my hearing. I worked as a trainer and was finding it harder to hear questions and was being told *I was speaking too softly when to me it sounded loud*.
- As a Retailer and Councillor, the ear blockage made *it more difficult to hear what people were saying*.
- Noisy background made it more difficult to hear what was being said or on tv, radio and at parties.
- Have Tinnitus in both ears and *miss important conversations*.
- Spoke with my GP about my hearing and he said *I couldn’t be deaf because I could speak*.
- Speaking on the telephone is difficult as use hearing aids in both ears.
- Generally, *communication became more difficult*.
- Dizziness as have Meniers Disease but was not aware at the time I had hearing loss.

Was there sufficient support in place to address these concerns?

12 out of 18 people felt there was sufficient support available to address their concerns.

However, it was suggested by some that having spoken with their GP about their hearing, and **nothing was offered.** One person was *left for over 10 years*. Wax removal by water jets, gave temporary relief but suction method was a big improvement. Some respondents felt there *was no support* and had to investigate hearing aids and pay personally. The *hearing aids are superb,* but nothing can prepare you for hearing reduction or loss.

How has your hearing reduction or loss impacted on everyday life?

Hearing reduction or loss can have a major effect on everyday life. One person shared that her husband became a *little irritated* that she did not hear him. She went to explain that she had to leave her job, something she loved. Walking down the street can be tricky as she does not hear noises from behind.

Another informed her family complained about the *level of noise on her radio/tv*. Hearing reduction or loss made conversations and speech difficult – having to repeat things. Some worry about not hearing the doorbell or that the TV can be heard by the neighbours.

Having hearing aids can be a worry as do not want them to get wet, fall out, getting lost, and remembering to take enough power supply when on trips. One person reported that her hearing aids have made a really positive difference and that she can now participate more fully in social groups.

Some people reported that they miss out on social activities and tend to stay at home alone. That they feel *not as connected to family and friends* as previously.

Feeling isolated and socially excluded and community groups

Three quarters (n13/18) felt their hearing change has left them feeling isolated and/or socially excluded. Yet only two have not accessed any community groups to help them feel less isolated or socially excluded. One joined a lip-reading group in 2019 but this stopped due to the COVID-19 pandemic and lockdowns.

Most responders (n16/18) felt confident communicating with others. Some reported they have difficulty hearing in a group setting, or not being able to use the phone except for text even with good quality hearing aids. One person shared they *only feel confident when they have a familiar person to lip read for them or an interpreter*.

Some suggested things that could help someone with hearing loss, such as:

- Speaking clearly and not shouting
- Being aware of different accents/dialects between speaker and listener and give clues on the content.

The introduction of masks and screens has made things more challenging.

Some find mobiles worse than a landline telephone, but this can be tricky with GP's even when noted on GP records, as it is never acted upon. People spoke of their irritation with having to tell people they are hard of hearing.

Support Services

The main areas of support for people are the NHS/Hospital, voluntary and community organisations and high street providers.

The main support services		
1	NHS/Hospital service	8
2	Voluntary organisations	6
3	High Street providers	5
4	Your GP	2

The overall experience of using support services was generally good.						
		1 Very Poor	**2**	**3**	**4**	**5 Very Good**
1	Quality of service	0	2	3	4	5
2	Ease of contacting the service	1	1	2	2	10
3	Ease of physically attending the service	1	1	3	5	6
4	Improvement in wellbeing	2	1	2	4	7

The preferred way of contacting support services was by phone or in person.

Preferred ways to contact support services.		
1	Phone call	10
2	Email	8
3	Visit in person	8
4	Text message	5
5	Video/Zoom	4
6	Post a letter	2

Beyond the original diagnosis:

- 12/18 did not have information about the condition or what happens next.
- 36/18 are unsure what aids were available.
- 15/18 have not received any support with their emotional wellbeing.
- 11/18 have not received support with everyday living.

Further needs and support

In response to the most used aid, most reported finding hearing aids helpful and the other suggested items were not used. Suggested tools used included: Cochlear implants, blue tooth to hearing aids, subtitles on TV and linking TV to MS Windows 10 to gain increased magnification.

Other impairments or disability apart from hearing reduction or loss

Apart from hearing loss 13 people other impairments/disabilities reported.

- Arthritis
- Fibromyalgia
- Gout
- Macular degeneration x3
- Pulmonary fibrosis.
- Neuropathy
- No sight in one eye, partial vision in the other
- Partially sighted/ certified blind/visual impairment x6

The impact of the COVID-19 pandemic

The impact of the COVID-19 pandemic and lockdowns for people living with hearing reduction or loss. Using face coverings has made **communication more difficult as unable to lip read**. A number of people reported they had difficulty taking off face coverings due to their hearing aids.

> *Lost a very expensive hearing aid when taking off the face covering.*

> *I could have up to four things behind their ears - glasses varifocal lens, glasses dark lenses and side shields, plus mask.*

Having to deal with these changes and challenges alone. Appointments to GP and the team at First Community Health and Care, changes to appointments from referrals, masks, and screens. Lack of transport to support these appointments has been a challenge.

Many have overcome some of the challenges, which has been a **continuous battle** by telling people they have a hearing issue. Specsavers have been very helpful to some. The **masks and screens have been a real barrier to conversation, just ask people to repeat and speak slowly**.

One person recorded being registered deaf and they prefer face-to-face interactions with interpreters – the same local interpreter.

The impact of Visual Impairment and Hearing Impairment

Only a few people we spoke to during our engagement work were living with both visual and hearing impairments.

This is Betty's story (*name changed for privacy)

Betty* was registered as severely sight impaired in her early 60's. A few years later her hearing impairment was diagnosed. It was difficult to get a hearing aid to fit at first. It was clear that Betty had been compensating her hearing loss by lip reading and had been doing this for many years. To be able to communicate Betty does need to see a person's face. Betty now has hearing aids, but the volume can still be tricky. The digital stuff has helped to amplify the sound.

'When I began to lose my hearing as well as my sight it was very frightening." After the diagnoses I was left to find my own way. I felt confident in my own home as I know where things are, but leaving the house was difficult. A member of the ROVI Team visited about six years or so after I was diagnosed and supported by providing some tools.

Since lockdown, my walking has deteriorated, I do use a walker but can only manage short distances. *I am afraid I may trip over something as I have had more trips and falls recently.*

Another person told us that during the pandemic her husband has been unable to access wax removal services. This means that he is both visually and hearing impaired and this affects his day-to-day living, confidence and impacts on her trying to support him.

YOUTH

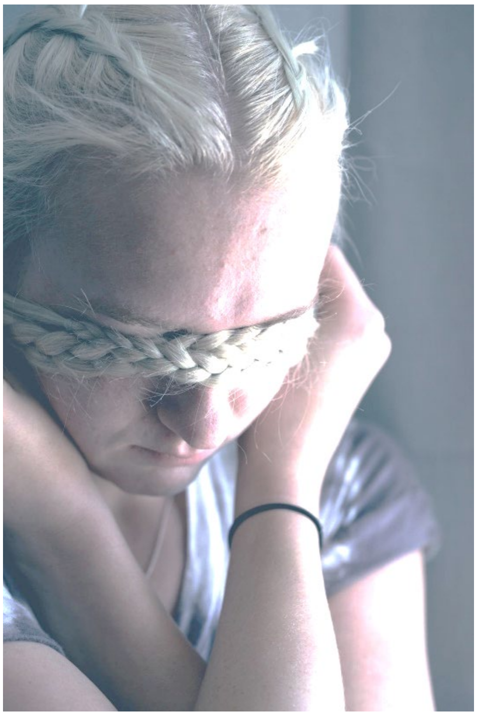
Children and young people sensory impairment

The following information has been obtained from Amaze[25] who hold the disability register for children and young people aged birth to 25 years. This register helps West Sussex County Council plan service and educational provision.

Note not all questions on the register were answered and this information only includes those who are registered over the last three years.

Analysing the register shows **about a third (1115) of children and young people on the register have a visual or hearing impairment.**

Hearing and /or Visual Impairment	Number	% of Register
Hearing Issues	310	8%
Visual Issues	648	17%
Hearing and Visual Issues	197	5%



Of the 5% identified as having both a visual and hearing impairment.

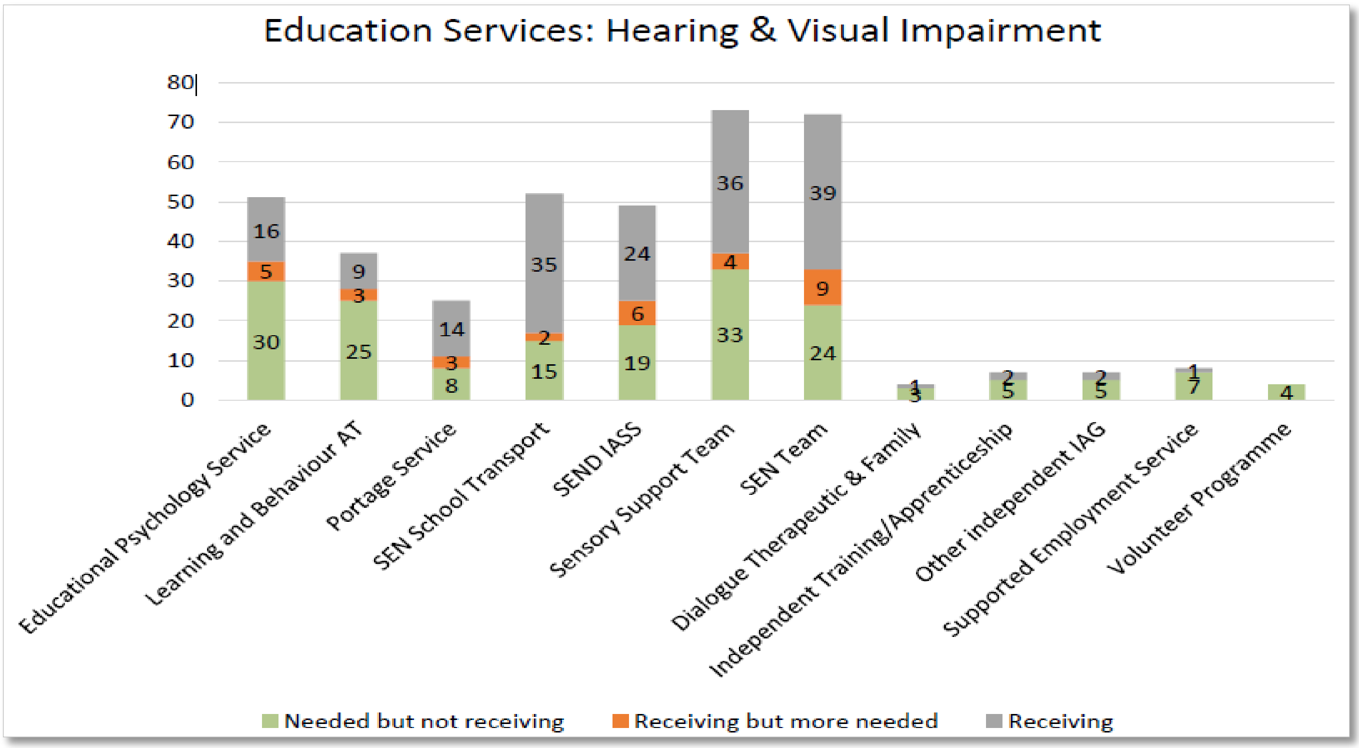
- 19 are profoundly or totally deaf with a visual impairment.
- 4 have a severe visual problem.
- None are registered as blind.

> *My son is 12 years of age and he has not been provided with any aids. I was told to buy a 'coloured ruler'! No-one has visited the school to assess him, and the text is classic and not in a larger font.*

---

[25] https://amazesussex.org.uk

The disability register shows if needs are being met, unmet or more provision is needed. This has highlighted that more service provision is urgently needed.



Parents of children and young people living with visual impairment

One mother shared that her son had been diagnosed as visually impaired at 7 years old (five years ago) and they have “ **received no help from anyone to date**.

Support at School - Support from mainstream educational places was described as poor and this affects the level of education for those attending. It was suggested that teachers should be trained in sensory impairment as they do not realise the impact of having the right size print and colour, etc...

Another mother who is caring for her daughter who is visually impaired said,

> “The ROVI Team taught her how to use Connect 12. She is now at college and has not received support from them. She has difficulty getting large print materials. It took three weeks to get sorted out. I am not happy about this. I did take things into my own hands and retyped the item into a larger font. The college could not understand how to make the materials in an appropriate size! The light in the classroom is also too dim for her to read in. (The white light provided by the ROVI Team is now taken into the college).”

Learning from the Children and Young People with Visual Impairment Survey

The children and young people living with visual impairment survey was completed by 13 people.

The age of the child when diagnosed with visual impairment was between Birth and 5 years. The main causes for the visual impairment were stated:

- Abnormalities unknown
- Brain Haemorrhage x2
- Genetic condition x2
- Congenital Cataract x7
- Encephalitis and sepsis from a viral infection.

Main worries or concerns

The main worries for parents at this time were wide ranging:

- How would this impact on his life?
- The difficulties associated with this.
- What if the surgery went wrong?
- The future and impact on education.
- Do teachers have enough training or resources?
- How the visual impairment affects balance etc.

> *A lot is being expected of me to bridge the gaps in service provision.*

Absolutely **everything was uncertain at this time**, no one could give me any idea of what the future might look like, even the tests were inconclusive, and no one knew how to support.

Due to the highly specialised treatment getting practical support was an issue to be able to attend appointments at Great Ormand Street Hospital (GOSH) especially when living more than 2 hours away.

Was there sufficient support to address these worries or concerns?

8/13 respondents believe there is not enough support available to address worries or concerns.

- We received no support with the travel to GOSH and at one point we went 3 times a week, including 2 operations. We struggled moneywise and I was recovering from a C-section. When my second child arrived, we had to ask family from the Midlands to help by looking after our eldest child, when attending appointments at GOSH.
- Everything is vague. My child had an **Education and Health Plan** (EHCP) in place very early. The nursery was great. Primary school is a joke, my child has had several Teaching Assistants - some have been nice but were replaced by the school with others, who treated my child horrifically.

  ❝I find that the school do not stick to what's in his EHCP and think if they are doing some of it, that's good enough!

  I feel that Schools need to be more accountable than they are, but they stick together when you question something. My child has had a terrible time, fortunately now left that school and we are now having to work on my child's self-esteem which has taken a massive battering.
- My child was viewed as naughty and so I was not being listened to about the concerns raised until someone supported me from the pre-school to support my concerns.
- I was sent home from hospital after finding out there was something wrong with my baby's eyes. They said they couldn't say any more than that and I would be sent an appointment from an ophthalmologist in the next few weeks. **❝I did not know if my baby was blind or not and was alone just waiting to be contacted.** After a week I got a letter to say I had an appointment for about a months' time... Nobody offered any support until I went to the doctors in tears asking for help.
- I had to travel a long way to get the correct support. As the hospitals and opticians all failed to diagnose.
- Tests were meant to be regular to help guide us as parents and help education. My child has not had any more tests for nearly three years. We are still none the wiser.

Support Services

Besides the parents and family, the main support comes from the NHS/Hospital, Local optician, the school and voluntary organisations.

Which services support your child?		
1	NHS services	10
2	School	10
3	Voluntary Organsations	7
4	Family	7
5	Local Authority/council	3
6	Local community	1

Reported services missing from this list included Sensory Support (lacking due to the COVID-19 pandemic), Parents and Carers Support Organisation and Personal Assistants.

The overall experience of using services was good.						
		1 Very Poor	**2**	**3**	**4**	**5 Very Good**
1	Quality of service	1	1	2	5	3
2	Ease of contacting the service	2	0	3	4	2
3	Ease of physically attending the service	1	1	3	4	2
4	Improvement in wellbeing from these services	0	2	2	2	4

The services reported as working well and have been useful to respondents included:

- Sensory support has been extremely useful when actually allowed to visit the school. At the moment teachers rely on myself to help with both kids.
- Parent and Carers Support Organisation[26] (PACSO)
- 4Sight Vision Support and RNIB
- Local optician – very professional in providing and fitting glasses with a GOSH prescription.
- The consistency of the hospital eye clinic staff has been excellent and building connection with my child has made the assessments easier to gain a true reading for the tests.
- The charity Look Sussex [27]
- Blatchington Court Trust are amazing so supportive and help build links with other families in similar position.
- Brighton Eye Hospital
- Chailey Heritage Trust[28] have been helpful in accessing education and monitoring.
- All voluntary sectors outside of county. This is a terrible county in terms of visual impairment support and accessibility (Chichester itself is terrible to navigate for a visually impaired persons, let alone a huge gap in services).
- The eye clinic in Cardiff.
- Guide dogs for the Blind custom eye service.

Respondents stated a number of areas where service provision **is not working well or useful**.

- Access to the service and knowing where to go for services was one issue, there is no one available for either of my children. I have contacted various charities and been told that both children '*are not blind and disabled enough*' to receive help. Yet both children received DLA.

---

[26] https://pacso.org.uk/
[27] https://looksussex.org.uk/
[28] https://www.chf.org.uk/

- Another issue was receiving **some support but not continuous** as exampled by this response: my child has not had any mobility support for a year. His cane is far too small and he's coming up to secondary school age where independence should be at a good level outside the home. Apparently, one is now in post and should give some support hopefully soon – no date given.
- There are gaps in education. West Sussex there is no primary school that has a visual impaired unit. West Sussex County Council's Sensory Support Team - the Qualified Teacher of children and young people with Visual Impairment (QTVI) assigned from diagnosis up until my child attended school in Surrey (age 8) shockingly had little or no useful knowledge of Cerebral Visual Impairment (CVI), my child's type of visual impairment. This has hindered his progress and success at school, leaving staff untrained for his needs. At best, the QTVI provided generic visual impairment equipment and the Functional Vision Assessment advised on enlarged books. A woefully inadequate level of support for a child with this condition.
- Specialist Teacher for visual impairment (STVI) are massively underfunded and can barely support a visual impaired child as the threshold gets higher every time funding is cut.

There are **few community opticians who are trained to work with children with special needs** making access to these more difficult.

One person informed that there was no support until her child was diagnosed.

Respondents stated that the Princess Royal Hospital eye services staff member was perfectly pleasant but so far no-one has successfully undertaken a full assessment or encouraged her daughter to comply. “ *I do not feel any confidence in local services*. The QTVI visited the school and gave generic advice only. She did not observe areas that may cause concern (reading books, PE, etc) and did not offer any specialist advice.

Generally, it was felt that the regular ophthalmology /NHS could be better, have better communication, and better services, as currently there is a lack of service provision.

Support/Information needed

When asked if there was any further information or support that could help parents and children, the following responses were received:

- Like to know about charities that can/are willing to support my children.
- Support with specific visual impairment conditions such as Nystagmus.
- The need of a Primary School in West Sussex with a Visual Impairment Unit.
- If my child returns to West Sussex for schooling and visual impairment support, he'd needs at the very least a QTVI, who has a high level of expertise in CVI.
- An automatic supply of two pairs of glasses - we know some children are given these automatically, even when from more affluent families and child has no other complex issues, but others, us included have to request second pair and the decision seems pretty arbitrary. This causes anxiety and genuine financial impact.
- Funding, for more staff, actual support networks for 'visually impaired kids' and a realistic plan of changing the design of Chichester to make it safe for blind/visually impaired person to walk around.
- Further advice and resources for schools and locally.
- More information regarding voluntary organisations. I have found out more from random adverts on Facebook which led me to Guide Dogs for the Blind.
- Knowing what services are available for sight impairment would be a good start.
- Only found two providers of day care services that could be suitable, following notice of no further funding being provided for sixth form college.
- Due to other health issues finding correct support is very difficult. Most services all lean towards learning disabilities or physical disabilities.

> *Not sure if this is the right place, but major impact on getting out in the community. The amount of dog poo on paths is horrendous, you can imagine how difficult this is for a cane user. Overgrown bushes are another difficulty my son has to overcome when out. Also, layouts with pavements when coming to a crossing. My son has had so many near misses, it is impossible for me to see a future where he will be safe. I really hope for my son, that these points are listened to as this is the reality of sight loss.*

Connecting to non-medical organisations

About half of respondents (6/13) had been told about non-medical organisations who could support their child. 7/13 parents stated not knowing about non-medical organisations that could support their child.

Communicating with Others

Most of the aids/tool/technology suggested in the survey was not widely used.

		No	Yes	Yes, not useful
1	Screen reader	11	2	0
2	Braille keyboard	12	1	0
3	Voice recognition software	9	1	3
4	Mobile apps	9	4	0

Other items used include audio reader and a kindle, iPad, magnification to enlarge font for writing and TV screen, Monocular, walking cane, wireless keyboard.

There were some training needs identified such as IT education.

Most (n11/13) parents stated their child feels confident in communicating with others. However, the following suggestions were provided.

- Being aware of the emotional aspects for the child of their visual impairment – anxiety over not seeing things.
- Professional need to begin by stating their name to the child.
- Time and patience.
- Children and adults being taught about visual impairment.
- Children with visual impairment should not need to explain to everyone.
- Appropriate spaces – appropriate signage, paths that are safe, bus drivers that have been trained.
- Support to make technology more accessible – magnifying screens for example.
- Not all children will respond verbally.

Further Needs and Support

5 out of 13 parents stated their child had unsupported/or could be supported better, needs. Some of the areas of need include:

- Support with anxiety – help and advice on this.
- Some children need 1:2:1 support to be able to attend clubs and none are available within West Sussex.
- Support for home schooling – equipment and specific advice.
- Children being able to engage with sports due their visual impairment. The right support is needed – time of day and distance.
- Support needed to help vocationally such as Touch typing available in Hampshire but not in West Sussex.
- Access to services due to transport issues for example getting around Chichester, the routes.
- Support with technology – assessment of what they can do with technology to support the child's communication and play.
- Information and clarity for parents on what each professional role is.

Other disabilities

9/13 respondents stated their child has other disabilities or impairment.

- Anxiety
- Autism Spectrum Disorder
- Bowel and urinary issues
- Cerebral Palsy x2
- Development delay
- Downs Syndrome
- Dystonia
- Epilepsy
- Feeding issues – loss of gag reflex
- Hearing impairment x3
- Kabuki Syndrome (global development delay)
- Loss of balance
- Neurodegenerative condition
- Non-mobile
- Non-verbal
- Tracheostomy
- Type 1 diabetes – diabetes insipidus
- Various physical and behavioural issues

Additional challenges due to the COVID-19 pandemic

- Appointment delays and cancellations - hospital, ophthalmology, assessments. (x6)
- Glasses took 7 weeks to come.
- The **Sensory Support Team** have only visited once since starting reception in September. Even though needs additional support.
- Mobility Team keep cancelling appointments as they have no-one in post.
- Not being able to have friends visit.
- Loss of vital support clubs - Springboard/Wheel for all/Othello's Club/Riding.
- Unable to attend school even though they have an Educational Health and Care Plan.
- Loss of Support Networks.
- Increases in anxiety due to Covid.
- Social Distancing issues - my child needs someone to guide them as well as someone with her 24/7 for her other needs.
- Impact on parents having to support 24/7. Shielding.

> No one outside of my social network has contacted me offering support despite being a lone parent and my child having multiple medical conditions.

How have these challenges been overcome?

Some of the challenges have been overcome by taking things one day at a time and just getting on with things.

- Had to just take things as they have come.
- Purchased various books to support my child's teacher about visual impairment.
- Saw some friends between lockdowns.
- Hospital eye appointment very soon.
- From September 2020 the Educational Health and Care Plan is reinstated.
- Have just had to wait it out – this has impacted negatively on my child's ability to engage in at home schoolwork.

Learning from the Children and Young People with Hearing Impairment Survey

The children and young people with hearing impairment survey was completed by 22 people. The hearing impairment was diagnosed between birth and 9 years of age. The causes of hearing loss were due to:

- Brain injury or other injury (x2)
- Chromosome deletion
- Change syndrome
- Congenital (x4)
- Meningitis
- No found cause (x9)
- Premature birth (x2)
- Sensioneural

Main worries at diagnoses

The main worries for parents at diagnosis included lack of advocacy, communication needs for the child and family.

- My child's speech would not improve. Or how to communicate with them
- With all the health problems my child faced just lucky that they were alive.
- Communication, how will my child learn to speak, will they ever understand, be able to speak, how would we manage, what would my child's life be like?
- Didn't know what we needed to do to make sure our child had everything they needed.
- Not knowing what it meant to have a deaf child or what support was available, or how to find it.

> We had no experience of deafness, had no idea what to expect or how to deal with it or support, which was terrifying. Her actual level and type of deafness wasn't confirmed until she was around 18 months. The ANSD (Auditory Neuropathy Spectrum Disorder) made it difficult (as did she) with testing. This made helping her and understanding everything harder.
>
> We worried an awful lot about communication, especially as we couldn't afford to do any BSL courses. We didn't want a qualification, just to be able to basically communicate. Most basic classes cover things like knowing how to describe a job, or travel...which is totally irrelevant to a small child. You have to get to much higher level to learn relevant day to day communication which makes it even less affordable!

Was there sufficient support in place to address these concerns?

Three quarters (n16/22) thought the level of support provided to address their worries and concerns was adequate.

> *The National Deaf Children's Society is a great resource for many families.*

However, a quarter (n6/22) felt there were gaps, such as:

- No-one to teach sign language.
- No classes for families to learn BSL.
- The audiology team were fantastic but incredibly limited in what and how they could support.
- The Teacher of Deaf (TOD) was supportive but very thinly stretched, very limited in time and what she could support with.
- Very little support from the Speech and Language Team.

> I had to ask the healthcare professional to look into the 'Why'. The test was consistently showing loss over a long period of time with one ear worse than the other. Then a change where the other ear became as bad as the first one. There was no infection. There may be comfort in the process of '*monitoring*' but not enough focus on the 'why'.
>
> There seems to be a focus on hearing aids but not investigating 'why'. The health professionals in audiology do not make recommendations for you to take back to the school.
>
> There is no joined up service of health and education in mainstream schools.

Support Services

Which services actively support your child for hearing impairment?		
Answer Choice		**Response Total**
1	NHS services	19
2	Family	16
3	School	16
4	Local authority/council	9
5	Voluntary organisations	7
6	Others	4
7	Your local community	1

Other support: Cochlear implanted Children’s Support Group (CICS), National Deaf Children’s Society (NDCS), Greenway Nursery, Southampton cochlear unit.

Who does your child have hearing related appointments with?		
1	NHS /Hospital services	21
2	Other	2
3	High street providers e.g., Specsavers/Boots	1

Other appointments at the Implant Centre and Southampton Hospital.

The overall experience of using support services for all children was rated 4 and above.

		1 Very Poor	2	3	4	5 Very Good
1	Quality of service	0	2	5	6	9
2	Ease of contacting the service	3	0	3	6	10
3	Ease of physically attending the service	0	3	5	8	6
4	Improvement in wellbeing from these services	1	0	5	4	12

The services that were reported as *working well and useful* for parents.

GOOD

Make short forward movement using closed hand with thumb up (1 or 2 hands).

- **Sensory support - Teachers of the Deaf (ToD) (x8).**
  ToD is fantastic. She's very stretched but always tries to make time. Sadly, she's limited in what she can do, but does always try to help.
- Services pre-school were great, felt very supported by the sensory support team.
- Southampton auditory implant service.
- The Children's audiology service at St Richards Hospital are spectacularly good with a brilliant team who actively ensure needs are met in the best possible environment.
- Support from St Thomas' Hospital and their ToD was really good, it felt far easier to approach than the local ToD.
- The unit at River Beach Primary School is incredible. They've done a lot to support us during the time there (now in secondary school).
- The Audiology Team at Royal Sussex Hospital Brighton has been fantastic. They went above and beyond to try and get tests done when she was a baby/toddler. Which was not easy! They also tried to point us in the direction of assistance when it wasn't something they could support.
- Greenway nursery absolutely amazing, especially the senco worker.
- Brighton, Hove, and West Sussex Deaf Children's society.

- The Elizabeth Foundation.
- Royal Sussex Audiology - quick response to any queries or equipment needs. Being able to have appointments locally at PRH Haywards Heath
- National Deaf Children's Society charity provides lots of useful info.
- The ear mould service is excellent.

Services that are not working well

- The team at Chapel Street make my child extremely anxious they are also very dismissive and abrupt.
- When my child began school, I felt abandoned as if we shouldn't be in contact with them. The TOD focus was school only.
- ToD services are so thinly spread they can't help and support as required.
- Deaf Children's Services was more easily available under previous lead than it is now. It is badly publicised. The only reason we heard of its existence was because they showed up at an NDCS event. Unable to help with our main issue of communication but went above and beyond to be available and to help with as many things as his restrictions would allow.
- The ear mould service is excellent - my child needs them for showering - however it is important to make sure you are offered a suitably experienced person in taking the moulds and for the fitting - we have had to return to have them re-done so many times which is counterproductive and uses up a lot of time for all concerned.
- Still Awaiting ENT, ABR and MRI four-years on. No hearing aids/implants have been offered to date. My child cannot hear at all on left side!
- Being in a mainstream school without access to a special unit has not worked in secondary school.
- My son has had a couple of referrals to Occupational Therapy, which only results in a sensory integration workshop that doesn't take into account working with a deaf child.
- We have to travel to Brighton plus there are forthcoming changes to services and a premises, move that will reduce space and the team will potentially not be able to deliver adequately simply due to location.

- Clinic communication.
- There is no support for learning BSL or how to communicate. This is absolutely vital. Especially early on when language ability is developing.
- Deaf Specialised Speech and Language support is incredibly difficult to get and can make such a huge difference. Normal speech and Language do not work with deaf children. You can't teach sounds with jingle bells or other instruments they can't hear! That is what one persistently tried with my daughter; despite being told repeatedly she couldn't hear them. Communication is so vital to be able to be a functioning part of society. Let alone as a child trying to learn and make friends.
- Deaf Children's Services is a nightmare to contact now. I had to fill in an online form that was clearly designed for reporting children at risk or being abused. If someone hadn't sent me the link to the right form to fill out, I would never have filled it out! All the wording and description is about children in distress. There is not one sentence about deaf children needing assistance with equipment or support. Apart from a confirmation email stating that was the correct form, and I would be contacted soon about three weeks ago; I have heard nothing.
- **Access to appointments for audiology is really difficult - school attendance is extremely important, and it is difficult to get an appointment outside of school hours - school attendance records penalise the child for appointments in school time**.
- It is also difficult to get appointments in the school holidays, the reason given: because the staff have children! Surely the service should be for the customers and not the staff.
- I don't feel that my son gets seen on time/appropriately at audiology- appointments always a long way after what is proposed.
- Communication between departments.
- Support / services with multi diagnosis such as deafness & autism to help support the child as a whole or understand how to work with a deaf child when looking at their other needs.

Other information shared

- There is no Chichester based group for my child to meet other children using hearing technology. Pre-covid, we met the Brighton Hove West Sussex group but most of them live far away.
- The National Deaf Children's society is very useful in filling the gaps.
- Teach parents sign language/Makaton. There's little point in teaching a child to sign when they don't teach the family, my child started school and would come home signing but we had no idea what he wanted or was saying. Very frustrating for him and us.
- Support and information regarding the move from school to college would be useful. How do we access support when my child leaves school to ensure the most appropriate support such as note takers and radio aid that he needs?
- More social interaction-based work with my child and their peers.
- Learning BSL properly would still benefit us. Although her needs have changed a bit with having cochlear implants fitted. It would've made the toddler years much, much easier for us and her. Now she can communicate audibly it's not quite as vital. However, when she's without her implants or in a noisy environment she can't hear anything... the few basic signs we've managed to teach ourselves have made that much easier to deal with. It also makes her feel less isolated.
- Am applying to change secondary school to one with a support unit.
- It was only at referral to specialist sensory paediatrician stage that we received further information about tests and organisations.

Non-Medical organisations

Over half of the respondents (n13/22) received information about non-medical organisations that could support. However, 9/22 **did not** receive any such information.

Communicating with others

We asked, do you use any of the following aids/tools/technology and do you find these useful to support you?

		No	Yes useful	Yes, not useful
1	Hearing aids	8	11	0
2	Loop system	13	5	0
3	Pager system	17	0	0
4	Mobile App	15	3	0

Most respondents (n18/22) confirmed their child was confident in communicating with others.

Some of the current *unsupported needs* for communication included specific equipment to support using the telephone, radio aid, acoustic tiles, or screens in school, ensuring that there is no background noise when speaking, and using text as well as the spoken word.

Unsupported needs

7 out of 22 respondents reported their child has unsupported needs. Teaching both the child and family members sign language, schools need a specific unit for sensory needs, support with autism and sensory needs. Support is needed for the social, emotional aspects, “my *child does not wear the processors when overwhelmed, anxious or in unfamiliar places.* The need for more regular appointments.

> “My child is doing really well. But we have had to do the research, really push, and stand our ground to get the help needed to get to this point. This should have been offered automatically and not had to be fought for. Services should be provided without research and easily available. There is a need to be told what services there are and what they do from the beginning – a pack listing the areas to find assistance.
>
> My child would be isolated and completely uncommunicative if we had not fought as we have. Now my child is part of society rather than being left on the side lines.”

Other disabilities or impairment

19 of 22 respondents stated their child lives with another disability/impairment.

- Asthma
- Autism and learning difficulties X4
- Bladder& bowel difficulties
- Cerebral palsy.
- Charcot Marie Tooth Disease - wheelchair user and mobility/dexterity difficulties Charge syndrome
- Chronic lung disease
- Cyclic Vomiting Syndrome
- Dyspraxia x2
- Down's syndrome
- Epilepsy x2
- Hypermobility type EDS x2Kabuki syndrome (his main issues are developmental delay and eyesight issues)
- Marcus Gunn Syndrome
- Sensory processing issues x2
- Significant dyslexia
- Speech and language
- Visual impairment x5

The COVID-19 pandemic and lockdown challenges

The main challenges during the COVID-19 pandemic and lockdowns have been the wearing of face masks and social distancing, as it has made it very hard for the child to hear and lip read. Many have just felt even more isolated.

There is concern that a lot of appointments have been cancelled, since last March 2020 and the effect of this. The routine hearing checks at the Implant Centre have stopped unless there is a specific problem. But it has *now been 16 months since the last check-up*.

The challenge of *home-schooling without access to speech therapy*. Having to shield generally *has added significant family pressure and taken its toll on the whole family*.

- My child's implant surgery happened just before the first lockdown. We had to cope with all the post-operative support and rehab whilst in full lockdown, with incredibly limited support. We had no or little communication other than writing or apps helping with speak - text (very inaccurate). Better signing at this point would've been brilliant.
- Getting medications.

- The staff at St Thomas's did what they could but trying to do audio work over an iffy Internet connection is virtually impossible. What should have been weekly appointments to slowly program her implants individually to fit, turned into large jumps in average programming as they had to be pre-programmed and sent out. The whole process has been incredibly difficult and stressful.
- Teacher of the Deaf (based at her primary schools' unit) did what she could to help as well. But with audio being the main way to communicate and was one thing my child couldn't manage; it was incredibly tough. My child has been very traumatised by it all and has lost confidence. My child has gone from outgoing, sociable, and independent to incredibly anxious and not wanting to leave us.
- My child changed up to secondary school last year, so has had a change of support and environment. Although the new school's been fantastic, this has not helped.
- Masks have been a big issue.
    - Even the clear masks are difficult as they fog up. We've had to postpone face to face appointments at **St Thomas's as they couldn't even wear clear mask (none have been cleared for use).**
    - She does not like wearing her mask with her hearing aid as it gets caught up as she is wearing glasses as well.
- She has great difficulty engaging in remote learning as most of it is by Zoom and she cannot lip-read so well or hear as it is an electronic sound. Due to the sensory overload of this and also videos playing/small fonts being used, the information processing and social communication demands, she is only able to be on a Zoom lesson for 20 of the assigned 40 minutes.
- When people wear masks, she cannot understand them especially if they are softly spoken or have an accent. If I were not with her, she would not understand what people were saying, be able to answer any questions relating to COVID-19, take part in her appointment.
- We don't know if our appointments were delayed due to COVID-19 or other reasons - they kept moving on later and later each time.
- West Sussex transport making two students share a taxi in different year groups, completely defeated the object of keeping year groups separated at school.

How have these challenges been overcome?

- Not really, we tried face masks with clear panels but they're really hard to breathe with (x4).
- Remained in family bubble for protection (x4).
- Able to still order spare parts for my child’s processors through Cochlear direct.
- The audiology service offered updates and consultation plus face to face when possible, with good measures in place to protect.
- Sunflower lanyard and badge, encouraging proactivity to ask people to remove masks.
- We've taken each hour as it's hit us. Each day was too much, especially early on in my child’s recovery. Paediatrician did try to put forward for counselling but couldn't even get onto a list. As Cyclic Vomiting and behaviour was seriously deteriorating, we decided to pay for private counselling. This has definitely helped and as an extension, for us. We're just incredibly lucky family that could help with the cost.
- We're looking into getting a hearing support dog in the hope it will help with regaining confidence.
- Everyday can be a challenge but we manage to get by.
- I have to speak for my child and 'translate' due to masks and people not speaking clearly to compensate hence I am communicating for her in a way which isn't helping her social communication development and difficulties.
- Getting others to collect medications when finally, available.
- New hearing aids were provided and set with previous settings.

The surveys demographics

As part of the engagement the four online surveys were active between 25 January and 21 February 2021.

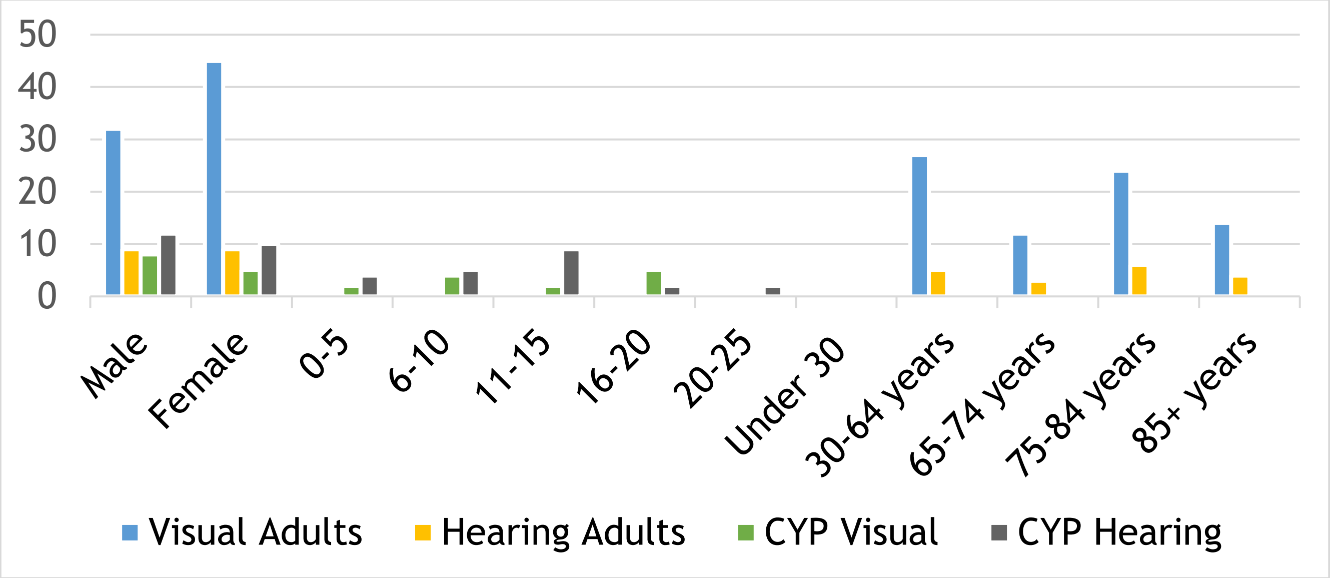
In all 130 responses were received:

- Adults with visual impairment 77.
- Adults with hearing loss or reduction 18.
- Children, and young people with visual impairment 13.
- Children and young people with hearing loss or reduction 22.

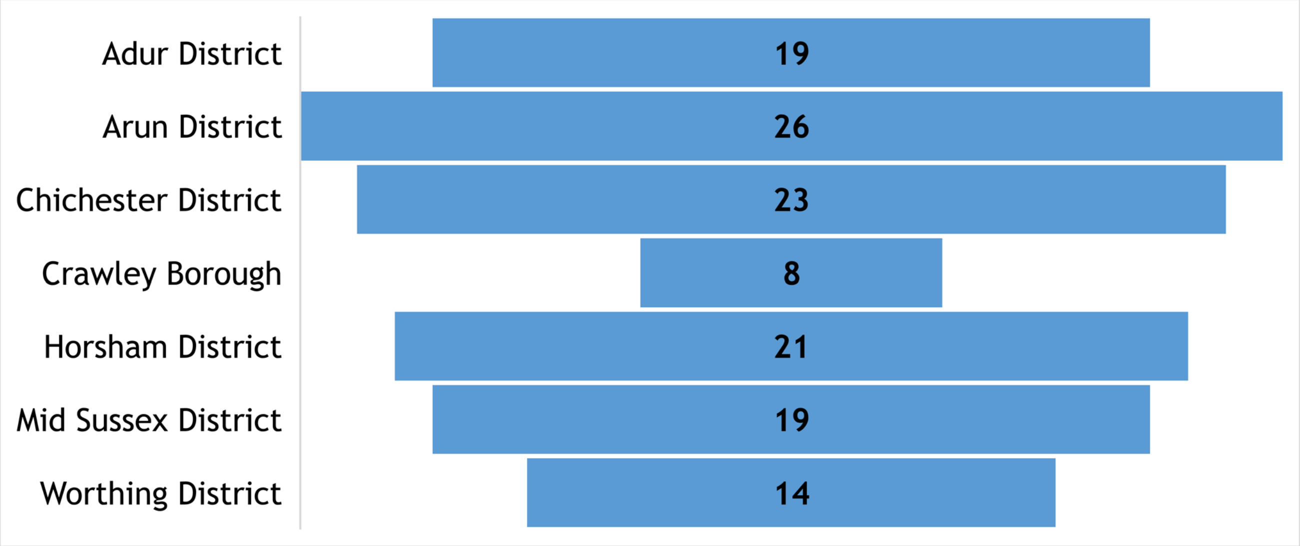
Whilst every attempt was made to make the questions easy to understand and answer, we are very conscious that the WSCC Citizen Space Consultation Hub portal did not offer a BSL version. Healthwatch West Sussex email and telephone was provided, and our helpdesk and staff supported 8 people to complete the surveys.

About the responders

Survey respondents' demographics



The respondents were from all of the Districts of West Sussex.



Acknowledgements

Healthwatch West Sussex would like to thank the following organisations for their support with this engagement.

Alzheimer's Society

4Sight vision support

Carers Support West Sussex
for family and friend carers

Macular Society
Beating Macular Disease

RNIB
supporting blind and partially sighted people

amaze
helping you through

west sussex county council

Appendix A Glossary of Terms	Definition
Adult UK Sight Loss Pathway	The Adult UK sight loss pathway offers commissioners and practitioners a unique tool to enable people with sight loss to get the right support at the right time and from the right person.
Any Qualified Provider	**Any qualified provider (AQP)** is a type of NHS contract, which allows non-NHS as well as NHS organisations to provide NHS services. The AQP programme aims to give patients more choice about where they receive selected health services.
Audiology Service Pathway	Step by Step guide to services.
British Sign Language Charter	Accessibility Statement on websites.
Eye Clinic Liaison Officer	ECLOs have lots of knowledge on eye conditions and helpful local and national services. By offering dedicated individual care, ECLOs can talk to you about your worries and give you advice on how to lessen the impact your eye condition may have on your life.
Eye Health Pathway	Clinical pathway for treating eye conditions.
Health and Care Scrutiny Committee	The Health and Adult Social Care Scrutiny Committee is responsible for the overview and scrutiny of: • Adult's Social Care Services • Adults' Safeguarding • Coroner and Mortuaries • Dementia services • Drug and Alcohol Action • Health and health partnerships • Public Health • The review and scrutiny of the planning, provision, and operation of health services in West Sussex
Low Vision Service	The Low Vision Service is a statutory universal service for people with a vision impairment.

Rehabilitation Officer Visual Impairment	The main aim is to work with people who are visually impaired or who have a combined visual impairment and hearing loss (dual sensory), in their own homes to allow them to be more independent.
Royal National Institute for Blind People	Charity offering support, tools and information to people who are visually impaired.
Sight Care Advisor	The Sight Care Advisors are trained nurses, employed by 4Sight Vision Support but based in the eye clinics at Southlands Hospital and St Richards Hospital, Chichester. We are available at the clinics to offer information, advice, and emotional support at this vital time for people with irreversible sight loss.
Sussex Health and Care Partnership	Across Sussex, the NHS and local councils are working together to improve health and care. The Sussex Health and Care Partnership is an integrated care system involving all NHS organisations and the local councils that look after public health and social care. We take collective action to improve the health of local people, to improve the quality of health and care services and to ensure we make the most efficient use of our resources.
Sussex Health and Care Partnership Ophthalmology Transformation Programme Board	This Programme will develop and deliver service transformation across several pathways, e.g., Cataract, Glaucoma, Retinal disease, Minor Eye Conditions, and cross-cutting themes i.e., Failsafe, Shared Care, Integration, Virtual Attendance, Advice & Guidance, Patient Initiated Follow-up, Standardisation, Electronic communication, and Image-sharing. It will be iterative, with new workstreams being developed over the life of the programme:
Sussex Integration Care System	Collective action to improve the health of local people, ensure that health and care services are high-quality and to make the most efficient use of our resources.
West Sussex County Council	The council is responsible for public services such as education, transport, strategic planning, emergency services, social services, public safety, the fire service, and waste disposal.

Appendix B Acronyms Used

Abbreviation	Meaning
ANSD	Auditory Neuropathy Spectrum Disorder
AQP	Any Qualified Provider
BSL	British Sign Language
CICS	Cochlear Implanted Children's Support Group
CVI	Cerebral visual impairment
DLA	Disability Living Allowance
DWP	Department of Works and Pensions
ECLO	Eye Clinic Liaison Officers
EHCP	Education Health and Care Plan
GOSH	Great Ormand Street Hospital
ICS	Integrated Care System
LVS	Low Vision Service
NDCS	National Deaf Children's Society
PACSO	Parent and Carers Support Organisation
QTVI	Qualified Teacher of CYP with Visual Impairment
RNIB	Royal National Institute for Blind People
ROVI	Rehabilitation Officer Visual Impairment
SCA	Sight Care Advisors
SICS	Sussex Integrated Care System
STVI	Specialist Teacher for Visual Impairment
ToD	Teacher of Deaf
VCSE	Voluntary, Community Social Enterprise Sector

Appendix C Website Links not as footnotes

Website	Link
Age UK	https://www.ageuk.org.uk/
Carers Support West Sussex	https://www.carerssupport.org.uk/
Citizen Advice West Sussex	http://www.advicewestsussex.org.uk/new-bsl-live-link-connect-with-us-via-a-bsl-interpreter/
Dementia Friendly Worthing	https://www.dementiafriendlyworthing.org/
Elizabeth Foundation	https://elizabeth-foundation.org/
Glaucoma NHS	https://www.nhs.uk/conditions/glaucoma/
Low Vision Service	https://westsussex.moderngov.co.uk/documents/s9429/Low%20Vision%20Services%20-%20RNIB%20Mapping.pdf
National Deaf Children's Society	https://www.ndcs.org.uk/
Retinitis Pigmentosa	https://www.rnib.org.uk/eye-health/eye-conditions/retinitis-pigmentosa
Sight Support Worthing	http://sightsupportworthing.org.uk/
Sign Live	https://signlive.co.uk
SpecSavers	https://www.specsavers.co.uk/
Springboard	hello@springboardproject.com
Stargardt's disease	https://www.moorfields.nhs.uk/condition/stargardt-disease#:~:text=Stargardt%20disease%20is%20a%20form,causing%20loss%20of%20central%20vision
Sussex Sailability	https://sussexsailability.org/
The Guide Dog Association	https://www.guidedogs.org.uk/
West Sussex County Council Deaf Services	county.deaf.services@westsussex.gov.uk
West Sussex County Council ROVI	rovi.visualimpairment@westsussex.gov.uk
Worthing Dementia Action Alliance	https://www.dementiaaction.org.uk

Appendix D
Footnote links

1	NHS England statistical waiting times.	https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/
2	Eye Health Pathway	https://www.nhsx.nhs.uk/key-tools-and-info/digital-playbooks/eye-care-digital-playbook/eye-care-pathway/
3	Liberating the NHS White Paper	https://www.gov.uk/government/publications/liberating-the-nhs-white-paper
4	British Sign Language Charter	https://bda.org.uk/project/bsl-charter/
5	4Sight Vision Support	https://www.4sight.org.uk/
6	Macular Society	https://www.macularsociety.org/
7	Alzheimer’s Society	https://www.alzheimers.org.uk/
8	Royal National Institute for Blind People	https://www.rnib.org.uk/
9	Adult Sight Loss Pathway	https://www.rcophth.ac.uk
10	Certificate of Visual Impairment	https://www.rcophth.ac.uk
12	RNIB Low Vision Mapping report	https://westsussex.moderngov.co.uk/documents/s9429/Low%20Vision%20Services%20-%20RNIB%20Mapping.pdf
13	Eye Health Pathway	https://www.nhsx.nhs.uk/key-tools-and-info/digital-playbooks/eye-care-digital-playbook/eye-care-pathway/
14	White Canes	https://deafblind.org.uk/deafblind-awareness-red-and-white-canes/
15	Blatchington Court Trust	https://www.blatchingtoncourt.org.uk/

16	Hidden Disabilities	https://hiddendisabilitiesstore.com/shop/please-give-me-space.html
17	Blind Veterans	https://www.blindveterans.org.uk
18	Red Cross	https://www.redcross.org.uk/get-help/get-support-at-home
19	Cliffs Action Plan – Winning against Age-related Macular Degeneration.	https://yoolaa.co.uk/cliffs-on-line-booklet-winning-against-amd/
20	Cliffs Action Plan – Winning against Age-related Macular Degeneration.	https://www.youtube.com/watch?v=JfGlf_jlWeI
21	Acton for Deafness	https://actionfordeafness.org.uk
22	Vision Express	https://www.visionexpress.com/
23	Boots Opticians	https://www.boots.com/opticians
24	Loxwood Medical Practice	https://www.loxwoodmedicalpractice.co.uk
25	First Community Health and Care CIC	https://www.firstcommunityhealthcare.co.uk
26	Amaze	https://amazesussex.org.uk
27	Parent and Carers Support Organisation (PASCO)	https://pacso.org.uk/
28	Look Sussex	https://looksussex.org.uk/
29	Chailey Heritage Trust	https://www.chf.org.uk/

Talk to us

If you have questions about the content of this update, please either call 0300 012 0122 or email cheryl.berry@healthwatchwestsussex.co.uk

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, local Government, and other providers and community organisations to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps.

For help, advice, and information or to share your story

We are the independent champion for people who use health and social care services. We are here to find out what matters to people and help make sure their views shape the support they need.

We also help people find the information they need about health, social care and community and voluntary health and care support services in West Sussex.

ADVICE AND INFORMATION

Here to help you on the next step of your health and social care journey

We have the responsibility to make sure that the Government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

0300 012 0122

@healthwatchwestsussex

@healthwatchws
@NHSadvocacy

@healthwatchws