Cumberland Council

Cumbria Deaf Association

healthwatch Cumberland

NHS North Cumbria Integrated Care NHS Foundation Trust

Lived Experience Network

Access to Statutory Services for the Deaf Community

Carlisle & Whitehaven

March - April 2025

Contents

Introduction

The Cumberland Lived Experience Network organised and hosted 2 meetings (Carlisle and Whitehaven) with Voluntary, Community and Social enterprise (VCSE) organisations, Healthwatch Cumberland and Cumberland Council to develop a network of lived experience practitioners with a purpose of enabling knowledge transfer and good practice sharing to improve health and care outcomes for the population of Cumberland and in particular the hard-to-reach communities.

Five members of the West Cumberland Deaf community attended the second workshop in Whitehaven and in sharing their Lived Experience highlighted significant problems with access to statutory services resulting in significant health inequalities. Population health data signposts that the deaf communities will experience significant challenges with their physical and mental health (Elmond et al., 2015; Alexander et al., 2012).

See **Appendix E.** for Reference List

The Lived Experience Steering Group agreed to host a special interest group (SIG) for the deaf community and invited the Cumbria Deaf Association (CDA) to collaborate with the network to gain a deeper understanding of the challenges facing the deaf community when accessing statutory care.

The group decided to run two workshops, one in Carlisle and one in Whitehaven, to make it easier for people in more remote and isolated communities to take part and share their views.

This way more voices could be heard without the need for long travel.

Carlisle Workshop

Location: The People First Conference Centre, Carlisle
Date: 27th March 2025 1-3pm

Attendees

CDA (Cumbria Deaf Association)
Kelly - British Sign Language (BSL) Trainer
Nicola - Interpreter

Cumberland Lived Experience Network
Sally Thoburn, **Healthwatch Cumberland**
Suzannah Brookes, **Healthwatch Cumberland**
Pamela Martin, **NHS North East North Cumbria Integrated Care Board**
Chantahl Rodwell, **Cumberland Council Adult Social Care**
Chris Lloyd, **North East North Cumbria Regional Research Delivery Network & National Institute for Health and Care Research**

NHS NCIC FT Patient Experience Team (Acute Hospitals in Carlisle and Whitehaven)
Sylvia Atherton, Patient Experience Manager
Nicole Cottingham, Patient Experience Facilitator

Carlisle and District Nurse Team
Rebecca Simpson, District Nurse Team Lead

Lived Experience Methodology

The Lived Experience Network Team (LEN Team) used a loosely structured form of Appreciative Inquiry to encourage the contributors to share their experiences in a safe environment. The Inquiry asked the participants to recount their experiences using the broad themes of:

- **GP appointments**
- **Community Care appointments**
- **Hospital appointments**
- **Dental Appointments**
- **Adult Social Care services**
- **Care Homes**
- **Children and Young People**
- **Financial Support.**

Appreciative Inquiry is a way of creating positive change by focusing on what is going well rather than what is going wrong. It encourages people to share their best experiences, imagine a better future and work together to make it happen

It was noted that there was only one participant from the Carlisle Area CDA group, who commented that the Patient Experience Team at the NHS Trust led by Sylvia Atherton had engaged regularly with the deaf community, particularly attending the CDA Coffee mornings and sharing better ways of contact. There was also a community hub in the region supporting appointment booking. CDA were also seen as the first contact for Social Care needs. Nevertheless, the sole participant who is also a CDA facilitator provided significant insights into the challenges facing their community in accessing care.

The detailed capture of the experiences can be found in **Appendix A**.

The headlines from a review of the experiences captured.

We have reviewed the experiences and identified what we believe of the failure modes of the issues and summarised them below. We have then developed recommended actions to begin to improve the accessibility to care for the Deaf community in the next section.

GP appointments

- Deaf patients not signposted throughout the system
- NHS staff training for dDeaf awareness inconsistent and not mandatory
- No Plain English FAQs and forms

Community Care appointments

- Deaf patients not signposted throughout the system
- Confidentiality

Hospital appointments

- Communications media not appropriate
- Insufficient interpretation capacity
- Deaf patients not signposted throughout the system
- Interpreters frequently not booked
- NHS staff training for dDeaf awareness inconsistent and not mandatory
- No plain English version of procedure info
- No Plain English FAQs and forms

Dental Appointments

- Virtually no access to NHS Dentists
- Private dentists will not pay for interpreters

Adult Social Care services

- Deaf service users not signposted throughout the system
- Local Authority staff training for dDeaf awareness inconsistent and not mandatory
- No multi-disciplinary team (MDT) approach for the deaf community -NHS, Local Authority (LA) and VCSE.
- Health and Social Care not joined up for access challenged service users

Care Homes

- Deaf patients not signposted throughout the system
- Health and Social Care not joined up for access challenged service users
- One size fits all care home strategy

Children and Young People

- Geographic Isolation
- Dependent on the interpretation service
- Deaf patients not signposted throughout the system
- Health and Social Care not joined up for access challenged service users

Financial Support

- dDeaf communities are vulnerable
- Confidentiality
- Plain English
- Appropriate communications made
- Local Authority staff training for dDeaf awareness inconsistent and not mandatory
- Health economics of policy impact not considered
- Health and Social Care not joined up for access challenged service users

Please refer to **Appendix A.** for more detailed context.

Whitehaven Workshop

Location: The Beacon Centre, Whitehaven

Date: 24th April 2025 10-12pm

Attendees

Cumbria Deaf Association

Shelley Harrison (CDA)
Nicola Alloway (CDA)
5 members of the local deaf community

Cumberland Lived Experience Network

Pamela Martin, NHS North East North Cumbria Integrated Care Board
Chantahl Rodwell, Cumberland Council Adult Social Care
Chris Lloyd, NIHR North East North Cumbria Regional Research Delivery Network

NHS NCIC FT (Acute Hospitals in Carlisle and Whitehaven)

Sylvia Atherton, Patient Experience Manager
Nicole Cottingham, Patient Experience Facilitator

Carer Support West Cumbria

Susan Papworth, Carers Health Worker

Lived Experience Methodology

The Lived Experience Network Team (The Team) used a casually structured form of Appreciative Inquiry to encourage the contributors to share their experiences in a safe environment. The Inquiry asked the participants to recount their experiences using the broad themes of:

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- **GP appointments**
- **Community Care appointments**
- **Hospital appointments**
- **Dental Appointments**
- **Adult Social Care services**
- **Unpaid Care**

Appreciative Inquiry is a way of creating positive change by focusing on what is going well rather than what is going wrong. It encourages people to share their best experiences, imagine a better future and work together to make it happen.

Unlike the Carlisle CDA group, the West Cumberland area does not have a hub and is only just beginning to get contact with the NHS patient services, therefore we had a great group, some of which attended the second Network workshop in Whitehaven in March and included a lady with Cochlear implants and one who was non-speaking.

The detailed capture of the experiences can be found in **Appendix B**.

The headlines from a review of the experiences recorded.

We have reviewed the experiences and identified what we believe may be root causes of the issues and summarised them below. We have then developed recommended actions to begin to improve the accessibility to care for the Deaf community.

GP appointments

- Is signage and language communications treated differently to spoken language?
- NHS staff training for dDeaf awareness inconsistent and not mandatory
- Deaf patients not signposted throughout the system

Community Care appointments

- Prescription Home delivery not provided throughout the County Hospital appointments
- NHS staff training for dDeaf awareness inconsistent and not mandatory
- No plain English version of procedure info
- Communications media not appropriate
- Deaf patients not signposted throughout the system
- Insufficient interpretation capacity
- Is signage and language communications treated differently to spoken language?

Dental Appointments

- Staff training for dDeaf awareness inconsistent and not mandatory Adult Social Care services
- Deaf patients not signposted throughout the system
- Insufficient interpretation capacity
- Communications media not appropriate

Unpaid Care

- dDeaf communities are vulnerable
- Deaf service users not signposted throughout the system

Frequently Found Issues

Impact on the Deaf Community

The narrative from both workshops is unsurprisingly similar.

NHS Services

- The deaf community face significant struggles to get appointments with GP surgeries, community services, hospitals and Dentists as the booking systems methods don't often enable deaf patients to book timely appointments. Telephone, SMS and on line booking rarely accommodates BSL, their primary language.

- Few staff in NHS services have been trained in deaf awareness and are consequently unprepared to assist the deaf patients. Deaf patients rely on family members to make appointments which can breach confidentiality of personal conditions. Deaf patients become stressed when having to overly rely on their families and want to live as independently as possible.

- The patient communication passport that the Patient Experience Team at the NCIC Cumberland Infirmary use identifies that the patient is deaf, but this does not always trigger the need for an interpreter nor recognition that the patient cannot hear nor read signage and information boards.

- Patients may arrive for the scheduled appointments only to find the interpreter has not been booked or does not arrive on time or at all and appointment is either conducted through a family member of signing friend (confidentiality lost) or the appointment is abandoned, and they go to the back of the queue. **The Accessible Information Standards** state that 'support from a communication professional (for example, a deafblind interpreter or British Sign Language interpreter) are required to meet the standard.

- The efficacy of interventions is often compromised when the patient, accompanying family or interpreters do not understand the medical jargon and are unable to convey this to the patient. It is arguable that proper consent to an intervention is not always given.

- There are considerable health inequalities inherent in communities with a low health literacy age (8 years old or even younger in North Cumbria) and it seems that the deaf community suffers a similar lack of adequate understandable communication about their condition or treatment.

Based on the Lived Experiences of the deaf communities in Carlisle and Whitehaven, it appears that the NHS services are not consistently following the Red Flag guidelines that require NHS patient records (Primary and Secondary) to contain a 'Reasonable Adjustment Flag' The following information was sourced from the North East and Cumbria Learning Disability website.

The Reasonable Adjustment Digital Flag is a locally and nationally available record which indicates the reasonable adjustments required for an individual. The Equality Act 2010 states health and care organisations must take steps (reasonable adjustments) to remove the barriers individuals face because of disability.

This is a legal requirement for all organisations. Cumbria PRIMIS Informatics have updated the EMIS toolkit for the Reasonable adjustments Digital flag in line with changes to the consent requirements of the flag.

https://necldnetwork.co.uk/work-programmes/digital/reasonable-adjustment-flag/

Social Care

Access to adult social services appears to be primarily through the Cumbria Deaf Association with very little awareness and provision for the deaf community to access the support.

Care Homes

There are only 2 specialist deaf enabled care homes in England. Neither of them are in the north of the country. Even if places were available the separation of the deaf person from friends and family would surely have an impact on their health.

The specialist homes are: Devonshire – Household for the D/deaf based in Derbyshire and Easthill Home for Deaf People located in the Isle of Wight. (see mapped locations plotted below.)

During the engagement sessions, several carers did not recognise themselves as carers—"it's just what I do"—highlighting the need for clearer communication about entitlements and support. This gap underscores the importance of culturally appropriate and accessible information to help people understand and claim their rights.

BSL Translation Capacity

The NENC ICB Boost Deaf Awareness training notes that the entire North East North Cumbria region has only 43 BSL interpreters. In the course of our workshop and in preparation we understood that there are BSL trained interpreters who have not been formally certified to provide interpretation. Given the emphasis and funding in the NHS for spoken language translation it does appear that the deaf community are further excluded from access to care.

Deaf participants emphasised a desire for more direct and autonomous ways of accessing Adult Social Care, without always having to rely on family or the CDA to initiate contact. This lack of independence contributes to increased stress and a sense of disempowerment.

We concluded that the frequently found issues in accessing services (NHS and Local authority) can be summarised in 3 steps:

1. Making an Appointment
2. Completing the appointment on time with an understood outcome
3. Accessing the required follow on or step-down care

Recommended Solutions & Potential Outcomes

The members of the deaf community, NHS patient experience and adult social care attendees suggested the following solutions which we have chunked up to identify complementary solutions in the following tables:

Communication

- Extend use of patient passports to primary care, Adult Social Care and Care Homes
- Develop BSL videos for FAQ's and information sheets
- Using Plain English for all communications will improve signing and therefore communication
- Captions or someone doing BSL to be on information videos, so deaf people don't miss out on information in waiting rooms (See Appendix D for examples)
- Pictures are much better than words in communications (See Appendix C)
- NHS NCIC Foundation Trust Business case for Audiology department screens
- Existing contact methods—such as text messages or telephone calls—do not work well for many Deaf individuals. Participants consistently expressed a preference for video-based or BSL-first options that offer real-time, visual communication.

Service/Pathway development

- Investigate VCSE support for prescription delivery
- Investigate use of technology with Deaf Wellbeing Network e.g. Ring Doorbells
- Investigate emergency call button availability
- Interpreters always to be booked – this should be done by GP when it's about healthcare
- Including deaf people in making improvements
- Link the deaf community into a Cumberland HDRC project
- Working with CDA as they are already established in the community

Service/Pathway development continued:

- Communication passports
- Create a regular MDT for Deaf patients with Primary and Acute Care, Adult Social Care and VCSE
- Coproduce the development of a Adult Social Care Deaf Access Service
- Making sure patient record clearly identifies patient is deaf
- Learning from good examples and sharing this to others
- A register of BSL translation capability in the statutory services
- Speech therapy and cochlear implants being pushed over BSL – need to keep promoting BSL so that members of the community don't get excluded later if cochlear implants stop working etc. Audiology departments don't think about BSL.
- Using AI (artificial intelligence) BSL translation for repeatable information and signage (Appendix D)
- Solution for unpaid carers on benefits - Integrate the Carer Support West Cumbria Service

Deaf awareness

- Additional education and briefing with Care Homes to support deaf residents
- Health and social care staff need deaf awareness training, refresher training regularly and BSL lessons
- Need more awareness of deaf culture – can ask CDA members to define this. Includes touching and tapping to get attention, lots of hugging etc.
- Could get in touch with patient participation groups (PPGs)
- Meeting audiology services to share access and communication problems – none of audiology staff have undertaken deaf awareness training
- Don't be frightened to interact with deaf people
- Deaf people treated fairly
- Attending CDA coffee mornings to pick up access issues and offer advice

Desired Outcomes

- The deaf community enjoy the same access to health and social care as patients who are not profoundly deaf.
- The deaf community are able to enjoy a greater degree of independent living
- Improved Health outcomes
- Improved quality of life
- Greater inclusion in society

Solutions Matrix

The output from the solutions brainstorm has been matched to the primary service providers to demonstrate that the common solutions apply to different statutory service in the following matrix.

Solution Matrix	Application		
Solution ideas	Primary Care	Secondary Care	Adult Social Care
Communication			
• Patient passports in Primary care, Adult Social Care and Care Homes	●	●	●
• Develop BSL videos for FAQ's and information sheets based on plain english text	●	●	●
• Picture cards for basic communication	●	●	●
• Upgrade waiting room screens to support BSL communications	●	●	●
Deaf Awareness			
• Additional education and briefing for statutory services to support deaf service users	●	●	●
• Health and social care staff deaf awareness training, refresher training and ideally BSL lessons	●	●	●
• Reach out to patient participation groups (PPGs)	●	●	●
• Present the findings to staturory services	●	●	●
• Informal outreach through attending CDA coffee mornings	●	●	●
Service Improvement -Processes			
• Cross-service Multi-Disciplinary Team approach for Deaf patients Primary, Secondary , Adult SC and VCSE	●	●	●
• Patient/Service user records identify Blind people	●	●	●
• Learning from good examples and sharing with others			
• A register of BSL translation capability in the statutory and voluntary services	●	●	●
• Include deaf people in making improvements	●	●	●
• Deaf person appt triggers booking of Interpreters			
• VCSE support for home care e.g. prescription delivery			
Service Improvement - Technology			
• Using AI BSL translation for repeatable information and signage	●	●	●
• Investigate use of technology with Deaf Wellbeing Network e.g. Ring Doorbells	●		●
• Investigate emergency call button availability	●		●
• Deaf patient appt triggers booking of Interpreters	●	●	●

The Art of the Possible

During the course of our conversations with the deaf community and a small snapshot of statutory services, it became clear that the current capacity of accredited BSL translators is inadequate to meet the demand to support timely access to services. We reviewed solutions that have been used by the deaf community through various organisations.

Basic Solutions

The North East & North Cumbria Secure Data Environment (NENC SDE) Team were challenged to ensure that the coproduced information booklets were accessible to the deaf community. Within 2 weeks at a cost of £250, they commissioned this video which can be accessed by this link. This communication model has been adopted nationally.

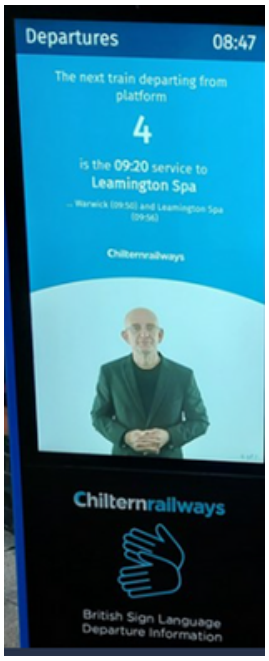
Dr Julie Young and Dr Lorraine McSweeney, researchers from Newcastle University described how they had engaged with the deaf community to use picture cards to explain basic nutritional information. The one page overview is included in the appendix.

https://www.northeastnorthcumbria.nhs.uk/media/lvkfyldb/upd001_whatwordstouse_1080p_master_240930_v4-1_bs_no_subs_1-with-bsl.mp4

Advanced Technology

At a recent quarterly network hybrid meeting, The North East and North Cumbria Deaf Wellbeing Network showcased the work of Dr Mark Wheatley from the RAD who talked about BSL and AI and introduced different types of "Avatars" including the video-based communications used by train companies.

Dr Wheatley also mentioned Signapse, a Cambridge (UK) start up company providing AI produced BSL videos for network rail and other transport organisations as well as the wider commercial sector.



Follow the link below to access the case study.

https://www.signapse.ai/case-studies/why-sign-language-accessibility-made-tarkentons-mental-health-project-actually-possible

Co-production and dDeaf community involvement in shaping services

During solution brainstorming, the Deaf community told us they wanted to be **actively involved** in shaping services. In response, the Co-Production Lead for Cumberland Council Adult Social Care and Housing, Chantahl Rodwell, is working alongside a commissioning officer, the Principal Occupational Therapist, and the Professional Practice Lead for Occupational Therapy to ensure that **future service development is meaningfully informed by lived experience**.

At the time of this report's publication, the Hearing Services tender was currently live, with a contract award expected imminently. While this initial commissioning phase has been time-limited, there is a clear commitment to engaging the Deaf community over the coming year to inform the ongoing development of the service. The intention is to carry out targeted co-production work with community members and key partners—including the Cumbria Deaf Association (CDA)—to better understand their priorities, identify where access currently breaks down, and explore practical solutions such as patient passports, accessible technology, and consistent interpreter provision.

A launch event with the commissioned provider is planned for September 2025 to raise awareness of the service provision and begin building relationships with the Deaf community. This will create a foundation for future engagement and help ensure that the service is visible, approachable, and informed by the people it serves.

Insights gathered through this engagement will be used to inform a formal review of the contract in 12 months' time. The process will involve mapping the lived experience journey of Deaf individuals accessing Adult Social Care and embedding that insight into future service iterations. This builds on the momentum generated through the Carlisle and Whitehaven workshops and reflects Cumberland's wider transformation efforts to embed culturally competent, inclusive, and person-led services.

Next Steps

We have created separate next steps recommendations following discussions with our partners.

Cumberland Council Adult Social Care Services (ASC)

1. Exploring ASC service user passports including the Red Flag.
2. Make communication more accessible (Plain English, BSL, and appropriate technology)
3. Improve interpreter access and consistency
4. Ensure the service is culturally competent and inclusive
5. Co-produce the forthcoming commissioning tender for BSL translation as noted on page 18.

Cumberland HDRC (Health Determinants Research Collaborative)

1. Write a specification to include the contents of this report in the HDRC secondary data review call for evidence underpinning the HDRC research priorities.
2. Incorporate the lived experiences, root causes and recommended actions into the HDRC secondary data review (once approved)

NHS NCIC FT

1. Identify a number of West Cumbria GPs to engage in access dialogue (Healthwatch?)
2. Request an audit of the use of the Digital Red Flag in patient records
3. Promote Deaf awareness in primary care

Voluntary Sector

1. Engage with CVS to identify potential voluntary sector support for the deaf communities

Expanding the Network and Cross Service Collaboration

1. Present a synopsis of the report at the NENC Deaf Wellbeing Network hybrid meeting in Carlisle (venue tbc) on September 24th to gain the support of the network. Ideally, we would be supported by members of the Deaf community.

2. Engage with the Deaf Wellbeing Network to develop links with the evolution of AI signed communications building on the examples in rail mentioned above.

3. Investigate low-cost solutions to produce BSL videos to explain standard services, booking appointment and navigating the care services.

Opportunities for other access disadvantaged/sensory deprived communities

After conversation with other citizen groups who experience similar challenges to access and fulfilment of service use such as the blind, neurodivergent and foreign language communities, there appears to be considerable opportunity to apply some of the solutions discussed above to the challenges these other communities face.

Appendices

Appendix A: Detailed Experience Capture from the Carlisle Workshop

NHS Service	Feedback	Failure modes
Case Study in the Hospital (Carlisle)	1. Consent for procedures, esp. radiology. 2. MRI scan – injection without consent. 3. No interpreter booked despite being asked. 4. They should know they can't go ahead with procedure without interpreter as can't get consent. Could be allergic to ingredients etc. 5. Medical jargon – don't understand what they have been told. 6. Barrier to consent. 7. Need easy read booklets. Written documents and letters from hospital rely on having strong level of English and use medical jargon. 8. Video interpreters not that great as Wi-Fi drops. A&E no signal inside at all. Can be blurry and if it's on a phone, can be too small to see. 9. Patient has an 18 year old son therefore denied an interpreter as he can sign. Son also has special needs which needs patient's support which requires an interpreter 10. Stigma attached to not being able to understand	Consent of Deaf patients is not correctly given as the patient usually does not understand what is going to happen. Communications media not appropriate Insufficient interpretation capacity Deaf patients not signposted throughout the system NHS Staff awareness
Hospital Appointments	1. Interpreter booking service is not consistent across departments. 2. New electronic patient record hopefully coming soon. 3. Interpreter booking passports/communication style passports a good idea. 4. Patients often don't know what they're going in for. 5. Doctors don't book interpreter, nor understand the need. 6.Patients end up agreeing to interventions without knowing what they are. 7. Medical terms need to be explained when signed not just directly translated as this is just the same medical jargon.	Deaf patients not signposted throughout the system Interpreters frequently not booked NHS staff training for dDeaf awareness inconsistent and not mandatory No plain English version of procedure information No plain English FAQs and forms

NHS Service	Feedback	Failure modes
Lifebox Service for pre-surgery assessment	1. Questions are not explained and don't always make sense. 2. This makes it daunting to fill out. Jargon. 3. There is no 'don't know' option, only yes or no.	No Plain English FAQs and forms
Online hospital booking for surgeries etc	Advice is to contact department and they would go through it with patient. However, would need an interpreter present for this.	Deaf patients not signposted throughout the system
GPs	1. It's GP's job to let hospital know an interpreter is needed. When its foreign spoken language, they can have a phone call interpreter but this is not possible for BSL. 2. Requires CDA to organise everything. 3. Deaf patients ask for face to face appointments and an interpreter. 4. Often receive a text message that you can't reply to (won't take incoming) or a text from GP saying no interpreter available. 5. 8 o'clock phone rush awful. Interpreters have to get up early to ring every doctor they can. 6. E-consult is available at some practices but often difficult to go through all the questions. 7. Deaf patients often have to book their own interpreters and push for face to face appointments. 8. Receptionists don't understand why would need an interpreter. They expect patients to use a family member. GP frontline staff need more deaf awareness training.	Deaf patients not signposted throughout the system NHS staff training for dDeaf awareness inconsistent and not mandatory No Plain English FAQs and forms
District nurses	1. Only accessible to book through phone call. Not accessible. They also call patient before appointment without knowing they are deaf, so sometimes nurse won't show up to patient's house as they haven't answered phone call reminder. 2. Could ask family or friend to call and refer them for district nurse, but sometimes are isolated and don't have people to ask to call for them or don't want to get family involved. 3. Many deaf people are vulnerable with exacerbating mental health issues	Confidentiality Deaf patients not signposted throughout the system

NHS Service	Feedback	Failure modes
CDA Activities	1. Small close community. 2. Coffee mornings every Monday 10-12 at Carlisle Hub in Vineyard Denton Holme. Run by 2 hearing members of staff. 3. CDA often have to do all the work to get people interpreters. 4. Often deaf people will pretend they understand to be polite, CDA trying to make sure they understand by getting interpreters. 5. Patients concern of over relying on children and family	Limited Resource 2 ½ FTE
Dentists	1. NHS dentists rare now. 2. Private dentists won't pay for interpreters.	Limited CDA Resource 2 ½ FTE

Adult Social Care Service	Feedback	Failure modes
Social Workers	1. Vulnerable people left without access to support because of communication barriers. 2. Social workers turning up at people's houses without much explanation and deaf community members confused or uncomfortable. 3. Phone calls and letters with jargon and not explained. 4. In past there were social workers for the deaf but this has been taken away. They were used to work with deaf children and deaf adults. 5. Communication passports needed	Deaf patients not signposted throughout the system LA staff training for dDeaf awareness inconsistent and not mandatory No MDT approach for the deaf community (NHS, LA and VCSE Health and SC not joined up for access challenged service users
Case Study – Deaf patient facilitator supporting deaf couple	1. Home Visits with basic assistance (not personal care). 2. Couple have mobility issues and are unsure what support is available or how to get it. 3. Communication channels are extended, complicated and slow. 4. Evidence of exacerbating physical and mental health	Health and SC not joined up for access challenged service users LA staff training for dDeaf awareness inconsistent and not mandatory
Care homes	1. Not clear how many BSL users are in local elderly care homes. 2. Isolated as can't communicate with others. 3. Care Home staff need to be trained in BSL. Rely on family to translate (if they can) 4. Good example from Morton care home? A member of deaf community living there near friends and family who can visit. 5. There are 2 care homes for deaf people in UK: Isle of White & Derby 6. Deaf people being moved to these care homes as staff don't know how to look after them. 7. Derby great care home but have to move far away.	Deaf patients not signposted throughout the system Health and SC not joined up for access challenged service users One size fits all care home strategy

Adult Social Care Service	Feedback	Failure modes
Support for Ageing Population	1. Vulnerable BSL users not getting home support as don't know about it or how to access it/ask for it. 2. Things need to be offered ad suggested as people don't know what support is out there. E.g. occupational therapy, housing repairs.	Communications media not appropriate No Plain English FAQs and forms
Children and Young People	1. Many families with deaf children do not sign 2. Less Deaf schools (although living away weakens family relationships 3. Deaf community isolation in rural areas 4. Children with partial hearing not funded to learn to sign 5. Technology solutions e.g. Cochlear implants not foolproof and require surgery 6. Deaf children not taught to sign and are excluded from the deaf community	Dependent on the interpretation service Deaf patients not signposted throughout the system Health and SC not joined up for access challenged service users Geographic Isolation
CDA	1. CDA staff great at getting through to social workers. 2. CDA does some community support work: Going to shops for people and help with advice, home tasks and online tasks etc – not personal care. 3. Don't get a lot of adult social care enquiries for an interpreter.	Limited Resource 2 ½ FTE Deaf patients not signposted throughout the system

Financial assessments/ implications	1. Often deaf community have relied on others to support and guide them for years and don't know how to ask for help. 2. Banking – phone calls 3. Could get lasting power of attorney to speak on behalf of them 4. People don't like to give bank details out 5. Not everyone understands what's going on in assessments – causes stress 6. Advocates and interpreters needed if someone doesn't have capacity 7. Social worker has to check they understand, but this all happens through an interpreter. 8. Deaf people with PIP often takes them above the income threshold to qualify for a funded interpreter 9. Deaf people often embarrassed that they don't understand what is happening and what they are entitled to	dDeaf communities are vulnerable Confidentiality Plain English Appropriate communications media LA staff training for dDeaf awareness inconsistent and not mandatory Health economics of policy impact not considered Health and SC not joined up for access challenged service users

Deaf Community Suggestions

- Captions or someone doing BSL to be on information videos, so deaf people don't miss out on information
- Health and social care staff need deaf awareness training, refresher training regularly and BSL lessons
- Interpreters always to be booked – this should be done by GP when it's about healthcare
- Including deaf people
- Working with CDA as they are already established in the community
- Communication passports
- All doctors forms to have alert for deaf patient so they can't miss that patient is deaf. And 'please don't phone this patient'.
- Learning from good examples and sharing this to others
- Speech therapy and cochlear implants being pushed over BSL – need to keep promoting BSL so that members of the community don't get excluded later if cochlear implants stop working etc. Audiology departments don't think about BSL.
- Need more awareness of deaf culture – can ask CDA members to define this. Includes touching and tapping to get attention, lots of hugging etc.
- Could get in touch with patient participation groups (PPGs)
- Pictures are much better than words in communications
- Deaf people treated fairly
- Don't be frightened to interact with deaf people

Appendix B: Detailed Experience Capture from the Whitehaven Workshop

NHS Service	Feedback	Failure modes
Hospital Communications and booking	1. Difficulty making appointments due to phone access only 2. Issues with access to interpreters—difficulty getting appointments and appropriate interpreters. 3. Need for better governance, interpreter standards, and oversight (e.g. DBS checks, right to choose interpreter). 4. Hospital letters not in BSL or plain English—often inaccessible. 5. Problems with timing and booking interpreters for appointments (esp. short notice). 6. Video BSL not always available — preference for face-to-face in some cases. 7. GP to Hospital Communications are poor 8. Patients' health at risk through delayed diagnosis and treatment 9. Referrers don't book or indicate need for interpreters 10. Cumberland Coast doesn't have a hub like Carlisle's to assist with appointments	NHS staff training for dDeaf awareness inconsistent and not mandatory No plain English version of procedure info Communications media not appropriate Deaf patients not signposted throughout the system
Attending Hospital Appointments	1. Interpreting provision is inconsistent (some good, some poor) – 1 patient had to use their son to interpret 2. Booked interpreters don't arrive when planned – sometimes due to parking 3. iPads for interpreting don't always work; staff unsure how to use them. 4. Deaf people worry they will be charged for DNAs – heard that a missed appt costs NHS £150? 5. Hospital staff not aware of patient being deaf even though stated on the forms 6. Signage and info screens in Hospitals don't make sense to deaf patients Trust has interpreters – who books them? 7. Cases where inability to clearly explain about the treatment or procedure prior to consent led to improper consent. 8. Interpreters or signing family members may not understand medical jargon.	Insufficient interpretation capacity Communications media not appropriate Deaf patients not signposted throughout the system NHS staff training for dDeaf awareness inconsistent and not mandatory

NHS Service	Feedback	Failure modes
Accessibility and Tech	1. Website accessibility tools suggested (e.g. for dyslexia, BSL). Doesn't always work 2. Hospital screen systems not accessible (need for clearer visual or signed communication). 3. Mini communication tools not accessible (e.g. TypeTalk). 4. Adaptive hearing	Is signage and language communications treated differently to spoken language?
GP Surgery Case Study	1. Husband rings for appointment, on hold for ages then no appointments available. 2. Appointment cancelled when interpreter not available, repeat the cycle. Interpreter may then not show or be late – West Cumbria travel challenges 3. Husband ill ,ring for appointment , kept on hold then receptionist not helpful. Daughter (who works) made multiple attempts. Patient worried about burden on family. Online booking not an option for all family members 3. GP practice not booking interpreter	NHS staff training for dDeaf awareness inconsistent and not mandatory NHS staff training for dDeaf awareness inconsistent and not mandatory Deaf patients not signposted throughout the system
Dental Care	1. No Interpreters 2. Practices don't always book an interpreter 3. Minimal Deaf awareness 4. NCICT has emergency and special care dental support	Staff training for dDeaf awareness inconsistent and not mandatory
Insights from NHS patient services	1.CDA have limited interpreter capacity – are other services available? Probable that deaf person would have to pay 2. Expand the patient passport that signposts the deaf persons need for interpreters right through the pathway 3. Attending CDA coffee mornings to pick up access issues and offer advice 4. Making sure patient record clearly identifies patient is deaf 5. Meeting audiology services to share access and communication problems – none of audiology staff have undertaken deaf awareness training 6. Business case for outpatient dept screens	

Adult Social Care Service	Feedback	Failure modes
Access to Services	Difficulty accessing ASC when Deaf—limited or no staff who can sign. Often referred through CDA (Cumbria Deaf Association), but need more direct ASC access. Text messaging service may not be sufficient or understood; preference for video or BSL access.	Deaf patients not signposted throughout the system Insufficient interpretation capacity Communications media not appropriate
Social Work Support	Unclear referral processes between CDA and ASC. ASC staff don't always have accessible contact methods or training. Need for a clearer pathway and consistent points of contact. No BSL capability in ASC Vicious circle GP-Acute Care – ASC	Deaf service users not signposted throughout the system Insufficient interpretation capacity
Unpaid Care	Example of carer supporting husband but facing issues (e.g. hospital parking, equipment). Unclear communication and inconsistent responses from professionals – do they know I'm deaf?. Carers need clear, accessible information	dDeaf communities are vulnerable Deaf service users not signposted throughout the system
Other	Transport support and rural access concerns. Request for communication aids (e.g. clear info, interpreter of choice). Equipment and practical support—issues with supply and clarity on access (e.g. stair lifts, kidney support, picking up prescriptions). Can be costly for carer to collect prescriptions	Home delivery not provided throughout the County

Appendix C. Newcastle University Involving Deaf people in research

Bridging the Gap: Empowering Deaf Communities in Health Research

Studies show that Deaf people who use British Sign Language (BSL) face health and wellbeing issues. It's hard for them to get accessible information about nutrition, healthy eating and exercise, like joining weight loss groups or gyms.

Newcastle University and the Newcastle Deaf Centre are working together to develop a programme that BSL users can attend to learn about nutrition, cooking and wellbeing.

March 2024

Researchers got funding from the Newcastle University Tilly Hale Foundation to find out what Deaf communities know about health, nutrition and wellbeing and where they might find information.

Collecting information from Deaf communities took time to ensure meaningful feedback – why?

- We wanted to connect with BSL users who were at school, college, work or who went to a Deaf Club.
- We had to get permission from people in charge of schools/ colleges or working with Deaf people to help recruit people.
- Understanding some words about nutrition and health in BSL can be difficult as not all words have a sign to match.

We asked Deaf people **to chat to their friends and classmates to collect information** about health, nutrition and wellbeing.

To collect information and talk about health and wellbeing, we designed some picture cards – **these were called visual communication cards.**

The visual communication cards were said to be **very helpful for collecting information.**

The information collected by Deaf people showed that BSL users had a **mixed understanding of health, nutrition and wellbeing information.**

Health, nutrition and wellbeing information needs to be **clearer and easier to find** for people who use BSL.

What next?

It's important to **include Deaf communities** in our plan for the nutrition, cooking and wellbeing programme.

We will **work with Deaf community members and the Newcastle Deaf centre** to apply for money to develop and test the programme.

Testing the programme will help researchers understand the **best way to share health information with BSL users.**

Where do Deaf community members get information about health, nutrition and wellbeing?

Adolescents Non-BSL users
11-16 years
Get info from school or Google, books or their sport's coach.

Young adults at college
21-22 years
Get info from the internet, staff at the college, or from friends.

Adults at deaf club
25-35 years
Get info from posters in GP surgeries, libraries or health centres and the internet.

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Appendix D. Visual (AI) Communications

Communication Passport

NHS
North Cumbria Integrated Care
NHS Foundation Trust

A communication passport is resource designed to support interaction between people with communication needs and their communication partners e.g. nurses, doctors. Communication passports provide a practical and person-centred way of summarising and sharing key information about a person and their communication for those who cannot easily share this information themselves.

Patients Name:	Patients Date of Birth:
Patients Home Address: Postcode:	Patients NHS Number:

This document outlines my communication needs because I am deaf and my first language is British Sign Language, I require a BSL interpreter to assist us to communicate with each other – for planned appointments please contact interpreters@ncic.nhs.uk for a BSL interpreter to be booked, for out of hours please contact Cumbria Deaf Association on 07824 139 687.

Appendix E. Reference List

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Appendix F. Glossary

Appreciative Inquiry - is a way of creating positive change by focusing on what is going well rather than what is going wrong. It encourages people to share their best experiences, imagine a better future and work together to make it happen.

dDeaf - The term brings together everyone who has any form of hearing loss. d describes hard of hearing, deafened and deaf people and D describes profoundly Deaf people and whose first language is often British Sign Language.

Health Economics - Health Economics is defined by how health care resources are allocated and how this affects health outcomes. In policy, it's important to recognise how relationships between stakeholders (patients, providers, policymakers) can inform policy decisions.

Health Inequalities - These are the unfair and avoidable differences in health across the population, and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them. The conditions in which we are born, grow, live, work and age can impact our health and wellbeing. These are sometimes referred to as wider determinants of health. (NHS England)

Multidisciplinary Team (MDT) - A group of health and care staff from different organisations and professions who work together to make decisions regarding patient treatment. For instance: a unit of healthcare professionals specialising in different fields, collaborating to provide individualised attention to patients, a collaborative approach where professionals from various backgrounds come together to plan and coordinate care. A MDT is essential for integrated care, ensuring comprehensive treatment and support for patients. (NHS England, Social Care Institute for Excellence)

Geographic Isolation - This can be defined as the physical separation of populations. Geographic isolation refers to the physical separation by barriers such as mountains, rivers, or distances.

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