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Accessible Information in Audiology: are we meeting the Standard?

Inconsistency, anger and frustration. Just a few of the many words used when discussing accessibility in Audiology. With many organisations not meeting the Accessible Information Standard, the BAA SQC team and their peers at ManCAD are looking to support services to ensure equal access not just in audiology but across healthcare sectors.

The Accessible Information Standard (AIS; NHS England, 2016c) is a 57-page document that describes the scope, terminology and requirements for different organisations. The associated Implementation Guide (NHS England, 2106a) is an 80-page document and gives advice on how to identify, record, flag, share and meet the needs of individuals. This document also describes levels of compliance with the standard: 'basic' to 'intermediate' to 'advanced' to 'exemplar' (NHS England, 2016a, pg 68-70).

'The Accessible Information Standard (AIS) directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss. It is of particular relevance to individuals who are blind, d/Deaf, deafblind and / or who have a learning disability, although it will support anyone with information or communication needs relating to a disability, impairment or sensory loss, for example people who have aphasia or a mental health condition which affects their ability to communicate'. (NHS England, 2016a, page 11).

The AIS equates to a huge amount of information to read, understand and apply in a consistent way.

What is our responsibility?

The AIS requires health and social care organisations to do five stages for adults who have a disability, impairment and/or sensory loss:
1. Identification of needs: a consistent approach to the identification of patients', service users', carers' and parents' information and communication needs.
2. Recording of needs:
   a) Consistent and routine recording of patients', service users', carers' and parents' information and communication needs.
   b) Use of defined clinical terminology in a nationally agreed coding system e.g. SNOMED CT codes.
   c) Use of specified English definitions indicating needs e.g., BSL.
   d) Recording of needs in such a way that they are 'highly visible'.
3. Flagging of needs: establishment and use of electronic flags or alerts, or paper-based equivalents.
4. Sharing of needs: inclusion of recorded data about individuals' information and / or communication support needs as part of existing data-sharing processes, and as a routine part of referral, discharge and handover processes.
5. Meeting of needs: taking steps to ensure that the individual receives information in an accessible format and any communication support which they need.

In summary, it is our responsibility to ask, record, highlight, share and take steps to address the needs of our patients to ensure they have equal access to information, advice and support.

Lived experiences of adults accessing Audiology

Variation in implementation of the AIS may lead to inconsistency in practice. Lived experiences demonstrate a lack of access to information for adults who are deaf and adults who use BSL (Bovino, 2020; Musker, 2020; Russell, 2020; Swinbourne, 2017). Negative experiences shared on Twitter produce a lot of engagement ('likes', 'retweets', 'quote tweets') and show feelings of anger and frustration at the inaccessibility of Audiology services. See Figure 1.

Access to services at each stage of the care pathway is a complex process requiring understanding of individual needs and preferences. The case studies presented show that access needs are highly individual and that adaptations to information and communication

support high-quality Audiological care.

Understanding Access in the UK

There are well documented inequalities in accessing healthcare for adults and children with intellectual disabilities and for autistic adults and children (Emerson et. al 2011). Contributors to health inequalities can include higher incidence of social determinants, non-compensated comorbidities, communication difficulties, risk behaviours and barriers to access (Emerson et. al 2011)

Inequalities are also evident in the accessibility of audiological services. One of the primary determinants of health inequalities reported by Emerson is challenges arising from communication difficulties. Across healthcare services use of the AIS has been variable however some disciplines have demonstrated greater understanding of the need for accessible information than others, (Jarrett et. al 2015). There is a dearth of information on the understanding and application of the AIS specifically in audiology services.

The Audiology, Learning Disabilities and Autism Project (ALDAP) funded by Health Education England South of England Intellectual Disabilities Programme and administered by Manchester University uses focus groups, interviews and questionnaires to explore the perspectives of individuals with lived experience, their families and professionals in the field on what barriers to audiological care exist for these populations and possible solutions. There is more information on the project website: https://sites.manchester.ac.uk/aldap/.

One avenue of exploration is the current use of the Accessible Information Standard and how this can be developed further within Audiology services. To

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ACCESSING AUDIOLOGY - TIM

CASE STUDY

Name

Tim

Access needs

Autism

Audiology needs

New referral into Audiology

Meeting the Accessible Information Standard

All providers of NHS care or other publicly-funded adult social care must meet the Accessible Information Standard (AIS).

Five steps of AIS
- Identify
- Record
- Flag
- Share
- Meet

Tim is sensitive to sensory information; he finds loud sounds, touch, and visual information, such as bright colours and images, overwhelming and distracting. Tim has good language skills, but finds verbal communication and social interaction challenging. He prefers written communication, with bullet points and some verbal support. Tim has found it difficult to hear his favourite songs at his usual volume setting. Tim visits his GP who refers Tim to an audiology department. The referral letter just states that 'Tim has autism'.

LEARNING POINT 1

The GP identified that "Tim has autism" in the referral letter, however autistic people do not consider themselves as a person with a disability, but instead autism is part of their self-actualisation and the preference now recommended by National Autistic Society is the use of "autistic adult" as opposed to adult with autism (https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism e.g. 'Tim is an autistic adult'. Autism is a spectrum of lifelong developmental conditions, encompassing a range of needs that affect the way people communicate, including sensory needs and executive functioning (such as memory and attention). Autistic people use a range of communication methods, depending on their needs. By not mentioning Tim's specific communication needs, stage 4 of the AIS has not been met.

Tim is sent a standard letter by Audiology. The letter includes several pages of text in small paragraphs, in size 12 Time New Roman font, and with single line spacing between paragraphs.It requests Tim to arrange an appointment over the telephone.

LEARNING POINT 2

Stage 5 of the AIS ('meeting of needs') has not been met. Tim finds closely compacted paragraphs of text overwhelming. To make documents accessible to a greater number of people, including those with autism, the use of 'sans serif' font (such as Arial) preferably in size 14, and double-spacing between paragraphs is recommended (NHS England, 2016a). It is vital to adjust and personalise appointment letters to meet the needs and preferences of autistic individuals. In addition, like many autistic adults, Tim finds verbal telephone calls stressful. Tim prefers written communication. Multiple contact methods should be available for Tim to book his appointment.

Tim arrives at the Audiology department. He is welcomed by Lisa, the audiology clinician. Lisa begins to explain what will happen in the appointment. She notices that Tim is not making eye contact and does not seem engaged. Lisa asks Tim how he prefers to communicate, and she provides examples, such as written text, images, verbally, or a combination. Tim says he prefers text in bullet points without pictures, with some verbal support. Lisa supplies information in this format.

LEARNING POINT 3

Stage 1 ('identification of needs') and stage 5 of the AIS have now been met. Importantly, different people with autism have different sensory and communication needs. Some autistic adults are over-responsive to sensory information – for instance, Tim finds images and colours distracting, but he requires verbal support. Easy read with images would not be appropriate for Tim. Some autistic adults are under-responsive to sensory information. It is vital to ask autistic adults how they prefer to communicate and whether they require images or verbal support. Lisa records Tim's communication needs using an electronic system, to ensure they are highly visible and flagged to staff at future healthcare appointments. By recording Tim's needs using an electronic flagging system, stages 2 and 3 of the AIS have now been met.

ACCESSING AUDIOLOGY - SHEILA

CASE STUDY

Name

Sheila

Access needs

Mild intellectual disabilities

Audiology needs

New referral to Audiology

Meeting the Accessible Information Standard

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Sheila resides in supported living accommodation. She communicates verbally and uses pictures to help understand complex information (e.g., EasyRead summaries). Sheila has reported problems hearing the TV and conversations. She is supported by her keyworker to visit her GP, who refers her to an audiology department. Sheila's intellectual disabilities are mentioned in the referral, but not her communication needs. Sheila receives a standard appointment letter from audiology.

LEARNING POINT 1

While the GP identifies Sheila's intellectual disabilities (stage 1) they have not shared how Sheila's communication needs can be met by the audiology department (stage 4). The audiology department does not provide information regarding appointments which would be accessible to Sheila (e.g. an EasyRead format) and therefore cannot fully meet her needs (stage 5).

Sheila attends the appointment with her keyworker. After testing her hearing, the audiologist suggests that Sheila might benefit from a hearing aid. They provide some hospital information sheets. Sheila's keyworker explains to the audiologist that Sheila cannot understand complex information in plain text form. The audiologist provides an EasyRead summary about hearing aids and points her to some online videos. Her keyworker goes through the EasyRead summary with Sheila to make sure that she understands it.

LEARNING POINT 2

The audiologist and keyworker are able to identify and share Sheila's communication needs during the appointment (stages 1 and 4). This allows the audiologist to provide suitable resources, while her keyworker ensures that this is tailored effectively to meet Sheila's communication needs (stage 5). To meet the accessibility needs, new formats of information may need to be created and/or sourced.

After the appointment, the audiologist enters Sheila's communication needs into their patient management system as part of the appointment notes. This information is accessible to all audiology clinicians. However, referring to it is not a routine part of appointment booking.

LEARNING POINT 3

The entry of Sheila's communication needs into her notes, partially meets the need to record communication needs (stage 2). However, these notes are not routinely referred to and so cannot be seen as 'highly visible'. Having 'Communication needs' as part of an appointment template would meet the requirements of stage 2. To meet the accessibility needs, services should adopt a range of technologies, integrating them into their IT and workstreams.

this end, a questionnaire has been written to understand the current application of the AIS in audiology services: https://redcap.link/yv6xro8q This questionnaire is open now and we would welcome your participation, thank you.

The outcomes of this questionnaire will then be used by the BAA SQC and partners to develop an AIS Audit tool specific to the needs of patients accessing audiology services by supporting services to identify areas where there are gaps in their provision of accessible information and resources that can be used to support improvement.

Figure 1

Future work of Service Quality

ACCESSING AUDIOLOGY - SANDIP

CASE STUDY

Name

Sandip

Access needs

BSL

Audiology needs

Long term hearing aid wearer, new to area

Sandip has moved to a new area and wishes to access his local audiology service. Sandip sees his GP and requests a referral to audiology at the local hospital. His use of BSL is highlighted in the referral. The department operates a partial booking system, and Sandip is sent a letter advising him to contact them to arrange an appointment. Only a landline phone number is provided.

LEARNING POINT 1

Multiple contact methods (such as a departmental mobile phone that accepts incoming text messages or e-mail address) should be provided, particularly if this is critical to appointment booking. Stage 5 of the AIS has not been met. Having identified the barrier to booking an appointment the department has the opportunity to meet stage 3 by flagging in Sandip's record the non-suitability of partial booking for his future care.

Sandip has to ask a colleague to phone and make an appointment. He arrives for his appointment 30 minutes early and the booked BSL interpreter is not due to arrive yet. The audiology clinician, Zane has had a non-attendance appointment. Zane did a Level 1 BSL course a few years ago and can remember some of the information that he learnt. Zane decides to start Sandip's appointment early.

LEARNING POINT 2

The BSL interpreter is an essential part of Sandip's care. While there are clear motivations to starting an appointment early, Sandip's needs can only be partially met without the comprehensive skills of the professional interpreter. Furthermore, Sandip may feel uncomfortable in this scenario, but not feel enabled to raise this.

Meeting the Accessible Information Standard

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ACCESSING AUDIOLOGY - YOSEF

CASE STUDY

Name

Yosef

Access needs

Severe to Profound deafness

Audiology needs

Long time hearing aid user, known to the service

Yosef has had severe to profound deafness since his mid-fifties. He relies on lip reading and cannot use the phone. He has a mobile phone for texts. He attempts to use technology e.g. email, but often has problems getting it to work. His wife used to attend all his health appointments with him in case he missed anything, but she is now terminally ill and he looks after her.

Yosef felt his hearing was getting worse. He could not call Audiology himself and the email never seemed to work so he had to ask his wife to call for him. Audiology did not accept text messages or have an online system for making appointments

LEARNING POINT 1

Learning point 1: Stage 5 of the AIS has not been met. Yosef is unable to make contact with Audiology himself but is forced to rely on others. Services should take steps to ensure appropriate communication is available. This may be a departmental mobile phone or video calling system. BT offer a free app to support text conversations over the phone https://www.relayuk.bt.com/

The Audiologist called him in for the waiting room. Yosef was sat watching the door very closely and jumped up as soon as any Audiologists come out, asking them if it was his turn. He found the waiting room very stressful, especially as the chairs did not face the door and the Audiologists did not always walk out fully into the waiting room before they shouted. He sometimes had to wait for 15 minutes and could not relax while waiting in case he missed being called for his appointment.

LEARNING POINT 2

Learning point 2: Calling Yosef in for his appointment by name is inaccessible for him due to level of deafness. Stage 5 of the AIS has not been met. Yosef needs a visual prompt when being called in for this appointment; this could be a visual calling system, a pager system, or his written name on a whiteboard or piece of paper.

Yosef was due to attend for his new hearing aids 4 weeks later. On the day of the appointment he got a phone call from the Audiology service. He could not hear what they were saying but assumed they were confirming his appointment. His wife as asleep and he did not like to wake her for help. He went along to the Audiology reception and they told him his appointment had been cancelled as the Audiologist was off sick.

LEARNING POINT 3

Learning point 3: Stage 1, 2, 3, and 5 of the AIS has not been met. Yosef's communication needs have not been identified, recorded, flagged or met. His communication needs should be noted and visible to all staff who may make contact with him, so he is not called on the telephone. Another form of communication should have been put in place to enable Audiology to make contact with him.

Meeting the Accessible Information Standard

All providers of NHS care or other publicly-funded adult social care must meet the Accessible Information Standard (AIS).

Five steps of AIS
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3. Flag
4. Share
5. Meet

Committee

- To better understand how Audiology services across the UK implement the AIS; please complete this survey to help us understand provision: https://redcap.link/vpctov0m.
- To gather service-user feedback, find out about their experiences, needs and preferences.
- To create an Audiology specific 'AIS Audit tool' to assess compliance and promote improvement.

Conclusions

Patient experiences suggest we are not consistently meeting the AIS in Audiology, leading to anger, anxiety, and loss of independence. Access needs are highly individual and need to be understood at the start of the pathway i.e., at referral. Appropriate access to information is essential from first-contact, assessment, rehabilitation, and life-long care. Lack of access to information and services compromises service quality, limits shared decision making, patient centred care and impacts service-capacity (e.g., non-attendances and failed phone consultations).

Our role in ensuring access to health care services and information goes beyond Audiology; Audiologists have a role in advocating for better implementation of this standard across healthcare services.

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ACCESSING AUDIOLOGY - PERINDA

CASE STUDY

Name
Perinda

Access needs
Severe visual impairment

Audiology needs
New referral into Audiology

Meeting the Accessible Information Standard

All providers of NHS care or other publicly-funded adult social care must meet the Accessible Information Standard (AIS).

Five steps of AIS
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Perinda was offered an appointment by letter. She was able to read the letter with the help of her magnifying aid, but it was two pages long so took her 3 hours to read in full. There was no map, so she attended with a friend who could help her find Audiology.

LEARNING POINT 1

The GP letter stated that Perinda had a severe visual impairment but did not say state her communication needs. Stage 1 of the AIS has not been met. The Audiology service sent a letter assuming this would be accessible for Perinda or that someone could read it for her.

She had a hearing test and was told she had a mild hearing loss. This was surprising as she felt she was really struggling. She was given hearing aids on the same day. The controls were very confusing, and the leaflet provided had very small words with lots of pages. She worried about how long it would take her to read it all. She also had memory problems so knew she would not remember all the information she had been told.

LEARNING POINT 2

The written information provided to Perinda was inaccessible. Stage 5 of the AIS has not been met. The following supports accessibility of written information for adults with visual impairment:
- Simple font, such as Ariel with double space (at least) between lines.
- Leaflets with enlarged text – prior to printing check the patient can read the font size from the computer screen (when screen size set to 100%). Adults with tunnel vision may not prefer large text.
- Contrast between font and background – black on white is ideal. Some adults may prefer yellow paper as white paper can cause glare.
- Adults may use mobile phone apps to enlarge text and/or convert text to voice. Information can be emailed to the patient so they can use a device to enable access.

Perinda got a copy of her report a few days later describing her appointment, this was also very hard to read as it was long with small, hard to read words. She did not know what 'sensorineural' and 'presbycusis' meant but they sounded serious.

LEARNING POINT 3

Perinda's access needs had not been recorded and flagged to ensure she got appropriate letters and written information. Stage 2 and 3 of the AIS have not been met.

She tried to use the hearing aids but could not remember what to do. The leaflet was too hard to read. By the time she got to her follow up appointment 6 weeks later she was upset and felt like she had failed with her hearing aids.

Bovino, F (2020) [Twitter]. January 20th. Available at: https://twitter.com/biggsfe/status/1351883961836969985

Emerson, E., Baines, S., Allerton, L., & Welch, V. (2011). Health Inequalities and People with Learning Disabilities in the UK: 2011. Durham: Improving Health and Lives: Learning Disabilities Observatory.

Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read?. Journal of Intellectual Disability Research, 58(9), 822-829.

Jarrett, D., McGregor, S., & Terras, M. (2015). The use of accessible information in the healthcare of people with learning disabilities.

Musker, Z (2020) [Twitter]. November 24th. Available at: https://twitter.com/zmusker/status/1331190926128132096

NHS England (2016a) Accessible information: Implementation Guide v1.1. Available at: https://www.england.nhs.uk/wp-content/uploads/2017/08/implementation-guidance.pdf

NHS England (2016b). Accessibility Information Standard. Available at https://www.england.nhs.uk/ourwork/accessibleinfo/

NHS England (2016c) Accessible information: Specification v1.1. Available at: https://www.england.nhs.uk/wp-content/uploads/2017/08/accessilbe-info-specification-v1-1.pdf

Russell, J. (2020) [Twitter]. 20th August. Available at: https://twitter.com/Jane3Russell/status/1296349981654290432?s=02

Swinbourne, J (2017) Why I have trust issues with audiologists. The Limping Chicken. Available at: https://limpingchicken.com/2017/08/01/joanne-swinbourne/