

British Society of Audiology

Promoting excellence in hearing and balance



Practice Guidance:

Access to Audiology Services for Adults with Intellectual Disabilities

Date: April 2021

Due for review: April 2026



General foreword

This document presents Practice Guidance by the British Society of Audiology (BSA). This Practice Guidance represents, to the best knowledge of the BSA, the evidence-base and consensus on good practice, given the stated methodology and scope of the document and at the time of publication.

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Comments on this document are welcomed and should be sent to:

British Society of Audiology

Blackburn House,

Redhouse Road

Seafield,

Bathgate

EH47 7AQ

Tel: +44 (0)118 9660622

bsa@thebsa.org.uk

www.thebsa.org.uk

Published by the British Society of Audiology

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Authors and acknowledgments

Produced by:

The BSA Cognition and Hearing Special Interest Group and the Professional Guidance Group

Key Authors: Lynzee McShea (ed.), Siobhán Brennan, Jane Douglas, Thomas Doukas, Lynne Holtom, BJ Martin,

With Thanks To: Colin Beard, Mandeep Tank, Audiology at City Hospitals Sunderland NHS Foundation Trust, the Cognition and Hearing Service at Sheffield Teaching Hospitals NHS Foundation Trust, Community Health Team for Adults with Learning Disabilities at Guy's and St Thomas' NHS Foundation Trust

Declaration of Interests: None Declared

Citation

Please cite this document in the following format:

BRITISH SOCIETY OF AUDIOLOGY (2021), Access to Audiology Services for Adults with Intellectual Disabilities. [Online]. Available at: <https://www.thebsa.org.uk/resources/> [Accessed date]





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1. Introduction

This document gives guidance on the access of audiology services for adults with intellectual disabilities. In this document the term “adults” is used to denote the period after 16 years of age, though it is acknowledged that many individuals with intellectual disabilities do not transfer to adult services until later. It is proposed that the reader considers this document alongside companion BSA guidance such as:

- Audiological Assessment for Adults with Intellectual Disabilities.
- Audiological Rehabilitation for Adults with Intellectual Disabilities.

This document is not intended to provide guidance on specific circumstances. It is important that the person responsible for the audiological care of the client (the ‘clinician’) is appropriately qualified and uses professional judgement when deciding on the particular approach to be used, given the specific circumstances and the purposes of the care.

The term ‘shall’ is used in this document to refer to essential practice, and ‘should’ to refer to desirable practice. Unless stated otherwise, this document represents the consensus of expert opinion and evidence as interpreted by the Professional Guidance Group of the BSA in consultation with its stakeholders. The document was developed in accordance with the BSA Procedures for Processing Documents (BSA).





2. Definitions

Intellectual Disabilities

The World Health Organisation defines intellectual disability as “*a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development*”.

Whilst the term “learning disability” is the preferred term in the UK, (superseding historic terms such as mental handicap or mental retardation), “intellectual disability”, “developmental disability” and “learning difficulty” are also found in the literature. The term “intellectual disability” will be used throughout this document for consistency and to reflect global preference.

There are aspects of this document that may be applicable to adults with cognitive needs that have been acquired after childhood, including traumatic head injury or dementia, but the reader is advised to consult the relevant BSA guidance specific to these groups when this becomes available.

Carer

The term “carer” is used in a general context in this document to refer to any individual providing support to a person with intellectual disabilities, either paid or unpaid. Typically, unpaid carers are family members or friends of people with intellectual disabilities. Paid carers (often known as support workers) are employed to provide the levels of support required, which may vary from occasional input, to full support including personal care or feeding. Many people with intellectual disabilities rely on carers for advocacy, detection and management of health issues, including hearing (McShea et al, 2015).





3. Background

Though hearing loss is common among adults with intellectual disabilities, the exact prevalence is unknown. The most frequently used estimate is 40%, but is likely to be an underestimate, as many of the studies that have published prevalence estimates have relied on review of medical records or interview alone (Bent et al, 2015). High risk groups (e.g. individuals with Down's syndrome) are thought to experience a prevalence between 50-100% (Miller & Kiani, 2008). As well as sensorineural hearing loss, adults with intellectual disabilities are also more prone to ear infections, ear abnormalities and wax occlusion (Hardy et al, 2011; Fransman, 2006).

Despite this increased need, it is well documented that adults with intellectual disabilities have poorer access to services than the general population (Heslop et al 2013); despite evidence of benefit from amplification (e.g. McShea et al 2014), only a small percentage of adults with intellectual disabilities and hearing loss having been offered hearing assessment (Strydom et al, 2005) or hearing aids (Maatta et al, 2011). The reasons for poor access to audiology services have been summarised by McShea (2013), and include:

- The reliance of our healthcare system on self-referral, which is a barrier for those with limited communication or awareness.
- A lack of awareness / detection of hearing loss by carers and other advocates.
- Diagnostic overshadowing – where the symptoms of hearing loss are masked by, or assumed to be a feature of, a person's intellectual disability.
- Misconceptions around assessment, hearing aids and the capabilities of audiology.
- Barriers related to the hospital environment such as inaccessible information, signage, or fear around attending for appointments.





Accessibility of a service could be measured, not only by the visibility of the service, but also the ease of referring into it, and the experiences of those referred when engaging with the service. These three aspects will be covered in the remainder of the document.

4. Referral routes to audiology services

Referral from primary care is currently a prerequisite for accessing some audiology services. Primary care could therefore be described the “gatekeeper” to some specialist services. This in itself can be a barrier to access, depending on the opinions and attitudes of the referrer (McShea, 2015b), and the ease with which these referrals can be made. A mechanism for self-referral for hearing assessment (in a similar way to self-referral for sight tests, by which a person can arrange a test without having to first visit the GP) would arguably remove many of the current barriers to access. In the UK currently, there are three main referral routes from primary care to audiology services:

4.1 Any Qualified Provider (AQP)

AQP is an initiative from the Department of Health, which aims to increase patient choice by offering National Health Service (NHS) hearing services in a range of community locations. This means that NHS hearing services can be provided on the high street by independent, non-hospital providers. With commissioners offering a single tariff, the aim of AQP was to improve services by introducing competition to drive up quality. Although in theory this is a positive initiative, if a non-specialist service does not have the facilities to suitably adjust hearing assessment and rehabilitation required for those with intellectual disabilities this may add a delay to accessing care. Often, this group are unable to access routine services like those provided under AQP, and often have unsuccessful experiences in community services due to mis-referral. However, as both these high street services and hospitals clinics are packaged as “NHS audiology”, it serves as an additional barrier. If someone has an unpleasant experience, it





affects their perception of the service as a whole and may affect future engagement. Though the needs of people with intellectual disabilities and hearing loss could be met in the community by making the reasonable adjustments which can occur in hospital services, AQP is not a suitable vehicle for this. We re-affirm that it is inappropriate for these patients to be referred via AQP and that any provider of AQP services should refer back via the appropriate pathway.

4.2 Via an Ear, Nose and Throat (ENT) Department

Individuals with intellectual disabilities unable to have their needs met via an AQP pathway, require an alternative referral route. For many primary care services, this means referral to an Ear, Nose and Throat (ENT) department. However, for those with hearing concerns only, a referral via ENT could be considered as surplus to requirements, particularly if the individual is unable to complete a routine audiogram and requires a subsequent referral to audiology for a hearing assessment using alternative methods. Referral to ENT therefore lengthens the overall pathway for the patient, creating unnecessary delays to a final outcome / treatment. Typically, ENT consultations are shorter and more “medicalised” than audiology appointments, meaning that it may be more difficult to make reasonable adjustments within an ENT environment. As well as potentially increasing the fear and anxiety experienced by some people visiting a hospital environment, it goes against NHS England’s ethos of “*right care, right place, right time*”. For these reasons it is recommended that referrals are made directly to audiology.

4.3 Direct referral to audiology via a non-AQP pathway

Adults with intellectual disabilities should be supported to access mainstream / routine pathways wherever possible. An intellectual disability in itself is not a reason for alternative provision. In many cases, small reasonable adjustments are sufficient to facilitate mainstream access. However, many adults with intellectual disabilities will be unable to access routine pathways and will require a more specialised assessment (e.g. two tester assessment using techniques such





as visual reinforcement audiometry). The method in which a person completes a hearing assessment should not necessarily be classed as outside the remit of a direct referral system. It is recommended that audiology services do offer such a pathway.

5. Increasing visibility of Audiology services

As well as confusion around referral pathways and accredited providers, there are two additional factors which can reduce the visibility of appropriate audiology services for those with intellectual disabilities:

- The ability of primary care (the gatekeeper) to detect hearing loss.
- The attitude towards and awareness of audiology within the community.

5.1 Detection of hearing loss in primary care

Annual health checks were first recommended in 2006 by the Disability Rights Commission, in order to reduce the health inequities faced by adults with intellectual disabilities. These health checks should be standardised and should cover specific elements including chronic illness, medication, behaviour and a physical examination. Since their introduction, the health checks have been considered cost effective and effective in identifying undetected conditions (Robertson et al, 2010). However, the vast majority of published literature on annual health checking makes little, if any, reference to hearing loss. In most cases, where hearing issues were considered, the documentation related to ear wax occlusion only (Robertson et al, 2010). McShea (2015b) provides evidence of tokenistic hearing “assessment” in annual health checks; with a reliance on subjective caregiver opinion.

In the health check guidance material for GPs (Hoghton, 2010), the use of a “whisper test” is advocated to screen hearing in clinic. This is very unlikely to be sensitive or specific enough to detect hearing loss in this environment and will be inaccessible to those with more complex

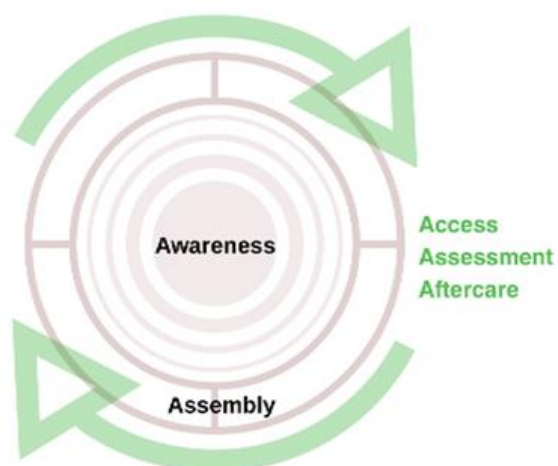




needs (as the test relies on physical touch and repetition of word/letter sequences). In addition, there is no indication of how to assess hearing, or of referring to audiology if the person is unable to participate in this assessment. McShea (2015b) states that the annual health check in its current format is not fit for purpose for detection of hearing loss and suggests that alternatives should be considered. One option is the use of point of care testing (POCT); which utilises “near patient technology”, to obtain objective assessment results (Giles et al, 2017). For hearing issues, this could include the use of oto-acoustic emissions (OAEs) to screen hearing and the use of hand held tympanometers during the annual health check, therefore providing robust evidence of hearing concerns, facilitating onward referral to audiology.

5.2 Awareness of audiology within the community

Increasing the reliability of hearing assessment within community settings would also be likely to help raise the profile of audiology within the community by increasing dialogue and contact between services. McShea (2016), suggests formation of a multidisciplinary team (MDT) and proposes the 5As model of Assembly, Awareness, Access, Assessment and Aftercare (designed specifically for audiology and intellectual disabilities) to facilitate this:



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A robust core of stakeholder assembly and multidisciplinary awareness means any developments made by the group are more likely to be sustained. This means that initiatives do not rely on individuals, as there is shared ownership. The focus shifts from service-centred to person-centred.

The focus of an MDT may be operational, strategic or a mix of both elements. Some MDTs are purely operational, and may form to discuss individuals known across services, to improve communication and outcomes. This can be particularly effective where an individual has multiple health needs that can be best managed by coordinated care (for example multiple procedures all achieved during a single general anaesthetic, for an individual with the highest levels of need). MDTs can be important vehicles for best interest discussions, particularly if the individual, their family or other advocates can participate. Most people with intellectual disabilities can have their hearing assessed by behavioural methods and assessment under sedation / anaesthetic should only be considered when all other options have been exhausted. However, such an assessment method can still be a valuable tool, particularly if it involves multi-professions to increase the benefit of the intervention.

There is no limit to the membership of an “Ears and Hearing MDT”, which may include audiologists, surgeons, primary care, community teams, speech and language therapists, support workers, social workers, caregivers and health facilitation teams. Some MDTs may meet in person, others may communicate via teleconference or online meeting. Secure email can be a useful tool to share information. Other MDTs may have a more strategic focus, using the group as a powerful, collective voice to drive change in their region. The Hearing and Learning Disabilities Special Interest Group (www.hald.org.uk) is a multidisciplinary group of professionals with this dual interest, who have similar aims, but operate on a national level.





6. Improving Experiences

Individual audiology services also have a responsibility towards improving access for their patients, not only by facilitating appropriate referrals, but also by facilitating contact with the service itself. Each service has a duty of care to make reasonable adjustments in this regard. These adjustments may relate to the timing or nature of the appointment, or may even begin before the appointment itself.

6.1 Preparation before the appointment

Adequate preparation prior to an appointment is essential. Heslop et al (2013) reported that a lack of awareness and a lack of reasonable adjustments are the main reasons why health care for adults with intellectual disabilities is deficient. The Accessible Information Standard (2015) should be used to support access to audiology services.

Identifying individuals with additional needs on patient management systems can facilitate appropriate preparation. Adults with intellectual disabilities are often encouraged to create a “hospital passport”; which includes useful information about the individual. Whilst these passports can be useful, not all adults have them and anecdotally, few are brought to appointments. Furthermore, the information contained in the passport focusses on inpatient visits to hospital and is not specific to audiology or hearing. It is therefore good practice for departments to use pre-assessment questionnaires which are audiology specific. An example of such a questionnaire can be found in Appendix 1. In many cases, minor details can often have a significant impact.

Sharing information with other professionals can also be useful. For example, if an individual is known to Community Learning Disability Teams, they will often have a wealth of information about that person’s communication and any other health needs that may impact on assessment

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and intervention. This team (and / or a hospital liaison nurse for those working in NHS Trusts), can also provide general advice on support and communication for those unknown to these services.

In addition to pre-assessment questionnaires, triaging tools are also recommended to aid prioritisation and planning. Effective triaging ensures that resources are used most efficiently and that the appropriate level of care is provided in the first place. An intellectual disability in itself should not justify a change in provision. Many adults with intellectual disabilities are able to access mainstream services with minimal adjustments / support and should be encouraged to do this wherever possible. Appendix 2 is an example of a triage screening tool. The tool can be administered face to face or via the telephone, to determine individual needs prior to assessment.

6.2 Appointment considerations

When providing reasonable adjustments, flexibility and individualised care should be paramount. The following list is not exhaustive, but provides examples of reasonable adjustments and considerations around appointments in audiology:

- Use clear and simple language in appointment letters, avoiding jargon or scientific terms where possible (see Appendix 3 as an example).
- Provide the opportunity to visit the department prior to an appointment to aid familiarisation and reduce anxiety. Alternatively, send picture booklets or online resources with photographs of staff, rooms and equipment.
- Schedule a mix of morning and afternoon clinics – some people may be more alert on a morning, others may prefer an afternoon appointment to give them plenty of time to get ready and travel.





- Once the patient has arrived for their appointment, try to see them as quickly as possible to minimise anxiety caused by delays or waiting around.
- Try to schedule sessions during less busy periods, or offer an alternative quiet room to wait.
- Generally offer longer appointment times, to allow the patient to feel at ease and less rushed. Include breaks if the patient finds this helpful. Alternatively, some patients prefer several shorter appointments.
- Try to minimise stimuli in the assessment room –remove clutter, consider the use of muted colours and lighting etc.
- Offer domiciliary appointments for those with the highest levels of need, and complete these in environments familiar to the patient, such as their home or day centre.

Generally speaking, the more comprehensive the information obtained in the pre-assessment information the better, as it gives the clinician information to tailor the session to suit the individual.





Appendix 1: Pre Assessment Questionnaire

You have been referred for a hearing test
It is useful for us to know some **information**
about you before you come to see us



Please **complete this questionnaire** and return it in the
freepost envelope provided

A **family member, friend or staff member** could help you
Everything will be kept **confidentially**

Personal Information



Your **name** _____

What do you **like** to be called? _____

Who is your **main carer or keyworker**?

_____ (name) _____ (relationship to you)

What is their **contact number**? _____

Your Health



Please tell us any **medical conditions** you have
e.g. Down's syndrome, dementia, visual impairment etc





Your Communication



How do you **communicate**? Please tick:

- I can speak fluently without any problems
- I have some speech
- I do not have any speech
- I use Makaton
- Other _____

How good is your **understanding**? Please tick:



- I can understand speech easily
- I can understand key words
- I can understand Makaton
- I am not able to understand speech or sign
- Other _____

Is there anything else we should know about how you communicate?





Do you use a wheelchair to help you get around?

Yes ✓

No ✗



Please tick any of the things that might be hard for you:

Someone looking in your ears

Wearing head/ear phones

Sitting still for about 10 minutes



What do you like to do? (e.g. Watch TV, meet friends etc)

1. _____

2. _____

Is there anything you do not like?

1. _____

2. _____

Is there anything else you think we should know?

Thank you – Please return this booklet in the Freepost envelope provided





Appendix 2: Triage Tool

Learning Disability Specialist Hearing Clinic

Name: _____ Hospital Number: _____ Date of birth: _____
 Address: _____
 Transport required: _____ Preference for appointment: _____

Contact details of Family member/Key worker:
 Name: _____ Relationship to Patient: _____
 Contact number: _____

Any concerns about their hearing? Yes/No

	Details
Pain (lasting more than 7 days in the past 90 days)	<input type="checkbox"/>
Discharge or Infections	<input type="checkbox"/>
Sudden hearing loss	<input type="checkbox"/>
Tinnitus (unilateral/ pulsatile/ affect sleep)	<input type="checkbox"/>
Verbal/ non Verbal	<input type="checkbox"/>
Imbalance when walking	<input type="checkbox"/>
Dizziness/vertigo	<input type="checkbox"/>
Do they touch/bang their ears	<input type="checkbox"/>
When watching TV/ Listening to music is it loud?	<input type="checkbox"/>
Are they due for any operations?	<input type="checkbox"/>
Any history/ family history of hearing loss?	<input type="checkbox"/>
Visual impairment	<input type="checkbox"/>
Mild/moderate/Severe PMLD	<input type="checkbox"/>
Tactile defensive	<input type="checkbox"/>

Favourite Music: _____ Favourite images: _____
 Attends day centre: _____ Typical activities: _____

Otосcopy: Rt _____ Lt _____
 OAEs: Rt _____ Lt _____
 Tympanometry/Reflexes: Rt _____ Lt _____
 Referral to ENT: Yes/No _____

Suggestion for plan of action: _____
 Single/Dual tester: _____ Test type: PTA/Soundfield Performance/CERA
 Home visit: _____ Potential amplification issues: _____








Appendix 3: Accessible Reports and Appointment Letters


Dear


I will come to see you at your home to assess how well you can hear.

 I will come to see you on Friday 26th June

I will arrive at 3.30pm 

 I will look in your ears

You will listen to some sounds through headphones 

 I will ask you questions about your hearing
I will ask your carers what they think about your hearing

I look forward to meeting you.

Yours sincerely





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