Practice Guidance:

Audiological Rehabilitation for Adults with Intellectual Disabilities

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OD104-91

General foreword

This document presents Practice Guidance by the British Society of Audiology (BSA). Practice Guidance provides a reference standard for the conduct of an audiological intervention that 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. Although care has been taken in preparing this information, the BSA does not and cannot guarantee the interpretation and application of it. The BSA cannot be held responsible for any errors or omissions, and the BSA accepts no liability whatsoever for any loss or damage howsoever arising. This document supersedes any previous Practice Guidance by the BSA and stands until superseded or withdrawn by the BSA.

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1. Introduction

This document gives guidance on the audiological management of adults with intellectual disabilities. In this document the term “adults” is used to denote the period after 16 years of age while 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 for working with individuals with intellectual disabilities such as Position Statement: Audiological Care for Adults with Intellectual Disabilities, Audiological Assessment for Adults with Intellectual Disabilities and Access to Audiology Services for Adults with Intellectual Disabilities. It should also be read in conjunction with the latest NICE Guidance and other guidance and protocols relating to healthcare for adults with intellectual disabilities some of which are referenced in this document.

This document is not intended to provide guidance on specific circumstances or on interpretation of results. It is important that the competent person carrying out, or responsible for, the audiological care of the client (the ‘clinician’) uses professional judgement when deciding on the particular approach to be used with each person being provided for (the ‘client’), given the specific circumstances and the purposes of the care, and the carer’s level of competency.

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.

Carer

Throughout this document the term "carer" is used in a general context to refer to any individual providing support to a person with intellectual disabilities, either paid or unpaid. Typical, 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

There are just over 1 million people in England with intellectual disabilities, which equates to approximately 2% of the population (Emerson et al 2008). Specific guidance is required in providing audiological care for adults with intellectual disabilities (AWID) for the following reasons:

- Hearing impairment is common among AWID, with estimates of the prevalence of hearing loss in AWID at 40 - 45% (Neumann 2006, Evenhuis 2001). Some pathologies associated with learning disability can also impact the auditory system (Pikora et al 2014) and the prevalence of hearing loss in people with profound and multiple intellectual disabilities is likely to be even higher (Evenhuis 2001).
- The relationship between learning disability and hearing loss is multiplicative (Carvill, 2001). Additionally, the impact of hearing loss is often underestimated (Pryce & Gooberman-Hill, 2012). There can also be an association with challenging behaviour (Timehin and Timehin, 2004).
- Despite the high prevalence of hearing loss in adults with intellectual disabilities the rate of hearing assessment is low (Strydom et al 2005; Van Buggenhout et al.1999). Reasons attributed to this include logistics (Evenhuis et al. 2004) and the misconception that hearing assessment is not effective for AWID (Andersson et al. 2013). The need for improved access to appropriate hearing assessment is widely recognised (Evenhuis et al 1998, Hardy et al. 2013).
- Despite evidence of benefit from amplification in this group (Evenhuis 1995, McShea et al 2014) studies have found only a small percentage of AWID with a hearing loss having been given hearing aids (Meuwese-Jongejeugd et al 2006, Maatta et al. 2011).
- The communication needs of individuals who require support for most areas of their lives that optimising communication between clients and their carers is crucial so care can be provided as closely as possible to the client's wishes. There are other factors that arise from intellectual disabilities that affect audiological care which will be expanded on throughout this guidance.

4. Principles

At the time of writing the NICE guidelines applicable to working with individuals with ID are specific to instances where there are additional considerations that may need to be taken into account, such as challenging behaviour, dementia and mental health needs. "Challenging Behaviour and Learning Disabilities" (2015) include a series of principles that should be adhered to, most of which are applicable to providing care for AWIDs with or without challenging behaviour. In addition, NHS England published a Service Module for Commissioners of Health and Social Care Services (2015) based around 9 core principles that care for AWID should be centred around. In addition to these guidelines, the BSA Practice Guidance: Common Principles of Rehabilitation for Adults in Audiology Services (2016) document also apply when providing Audiological care for this group. Principles from these documents which are directly applicable to Audiology provision are listed below:

"I have a good and meaningful everyday life"

A major step in meeting this provision is enabling inclusion; the opportunity for inclusion in activities, employment and education. There is evidence that appropriate Audiological care can contribute to this by improving communication, confidence and mental health. To work to this principle considerations during Audiological consultations should include;

- What lifestyle does this individual want?
- What aspects of this individual's communication may be problematic in involvement in activities of their choice?
- What Audiological management would be most appropriate for the activities, employment and education that this individual enjoys and participates in?
- What opportunities are there for supporting self-management?

“My care and support is person-centred, planned, proactive and coordinated”

Consideration of the wide range of family, friends and professionals involved in an individual’s life should be made. Questions that should be asked early on in the planning stages of care include;

- Who are the appropriate people to be involved?
- How can communication between the relevant people be maximised?
- What processes are in place to prevent errors in co-ordination of care?

There are many existing resources available that can be used to build models that meet these needs.

“I have choice and control over how my health and care needs are met”

The care for an individual should be multidisciplinary with the most important input to that team approach coming from the individual themselves. This applies as much in Audiological care for AWIDs as for any other care provision. Identifying individual needs, setting joint goals and making shared, informed decisions should be the focus of the first appointment and should continue throughout the programme of care.

“I get good care and support from mainstream health services”

A major factor in providing appropriate care for individuals with intellectual disabilities is the professional having adequate knowledge and education in the specific needs of this population. It is insufficient for staff to assume that Audiological care should be applied in the same way for AWID as the wider population.

Reasonable adjustments need to be in place to provide equitable care for AWID. The examples of reasonable adjustments in this document are not exhaustive and consultation with other disciplines and the clients and carers can provide further ideas and requirements to meet this principle.

"I can access specialist health and social care support in the community"

Providing optimum Audiological care is meaningless if there are such barriers to care that the target population has limited or no access to those services. Under-utilisation of health services by AWID is widely reported and it is imperative that Audiological staff themselves are involved in addressing these barriers. Close working relationships between hospital based Audiological teams and the Community Learning Disabilities Teams are an essential part of this work.

Appendix 3 gives an example of a toolkit to evaluate if services associated with these principles.

5. Hearing Rehabilitation

At the time of writing there is limited literature around amplification specific for AWID. There are however aspects of the auditory system associated with specific syndromes that can be taken into account. Some of these factors are discussed below.

5.1 Hearing Aid Provision and Alternative Hearing Technology

There are syndromes associated with intellectual disabilities and hearing loss such as Down Syndrome which present with smaller external ears than expected. For these individuals using the predicted Real Ear to Coupler Difference (RECD) values in fitting software may be inappropriate. Due to considerably higher incidence of earwax in people with Down Syndrome in comparison with the general population it is particularly important that RECDs re measured prior to fitting during periods of clear ear canals so these values can be used when REMs are not possible. AWID have a higher incidence of cranio-facial abnormalities which will not necessarily present in a symmetrical way, so if possible individual RECDs for both ears should be measured. At the time of writing it is not certain that the ear canal lengths of AWID have the same normative range as those without, so when measuring the RECD, software should be used to measure accurate probe placement as opposed to assuming a standard probe depth.

For clients who are tactile defensive, a de-sensitisation programme may be necessary for them to tolerate ear impressions being taken as well as the hearing aid which should be coordinated with the Occupational Health team. It is important to have a flexible client centred approach to this, including trial of an assistive listening device so they can experience the benefits of amplification.

Spare hearing aids and assistive listening technology should be available for AWID who have additional needs e.g. dementia, visual impairment, behaviour that challenges at no additional cost to the client.

At the time of fitting, the following strategies are useful to reduce the risk of hearing aids being lost and sharing information with the client's support networks. Appendix 1 shows examples of accessible appointment letters and reports. Customised training programmes should be constructed around an individual client's needs, which could include:

- An 'important to me' chart/passport with picture/symbol of hearing aid clearly displayed.
- Dedicated, named and customized box for the safe storage of the hearing aid.
- Training of client to clean their own earmoulds and request help with managing their own hearing aids.
- An available 'ear care' box with puffer, batteries, tubing etc.
- Designated carer/support worker with specialist training on hearing aid care and maintenance.

5.2 Training programmes (hearing aids)

Support from carers (paid and unpaid) is fundamental to a successful outcome. It is good practice to offer training to carers so that they are skilled and consistent in their support to the client. Where possible, engaging the client in the training supports their independent management of the aid(s) and offers them empowerment about how they would wish their aids to be managed.

Appendix 2 shows examples of training offered to carers to enable them to support the client to use their hearing aid. The training should include practice of identifying left and right moulds, orientation of the hearing aid, battery replacement, cleaning, re-tubing, trouble shooting and what to do when the aid goes wrong.

5.3 Follow up

AWID clients are more likely to require additional face to face follow up appointments to address concerns and make adjustments to their hearing aid/s. It is good practice for follow up appointments to continue until there is demonstrable evidence that the clinical goals have been met. Clear information about the review process and time scales given at the end of the follow up sessions can increase the likelihood of clients arranging appropriate review appointments. This information can also be included in the Audiology report shared with the client, carers, GP and the client's circle of support.

5.4 Access to repairs

AWID can lose skills very quickly when not part of a daily routine due to their cognitive and memory impairments. Delays in repairs or replacement of lost aids can lead to repeat desensitisation work to re-introduce hearing aids. A reasonable adjustment and good practice is to have a mechanism to enable rapid repair/replacement of hearing aids or hearing devices for this client group. This should be considered as part of the care pathway.

5.5 Access to Reviews/Reassessments

Within the AWID population there is a high turnover of paid carers and often poor hand over. This can mean that awareness and skills around supporting the client with their hearing aid is lost. Regular reviews and reassessments can reduce this. Many Audiology departments offer a hearing aid review every 2 – 4 years for this group.

6. Applicable Audiological Outcome Measures

In addition to quantitative outcome measures, the qualitative experiences of individuals and their caregivers can be a powerful indicator of the benefit of rehabilitation / intervention (e.g. McShea, 2015).

In order to identify the possible impact of habilitation it can be useful to identify the cognitive (developmental) stage of the client both before and after the habilitation period. There are various methods that are recommended. These include:

- ASHA (Developmental milestones in communication)
- NAMES (Nottingham Auditory Milestones)

Outcome measures such as the Client-Oriented Scale of Improvement (COSI™) should be carried out before and after rehabilitation. This can and should be carried out with the support of the client's family and key worker if possible.

Undetected hearing loss may also be incorrectly labelled as challenging behaviour (Miller & Kiani, 2008). Challenging behaviour is defined by Emerson as: "A behaviour of such intensity, frequency or duration that the physical safety of the person is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities" (Emerson 1995, p44).

The term "challenging behaviour" is no longer used in the way it was originally intended. Rather than a label, the term was introduced to highlight the fact that support is a shared issue, and that poor support could lead to behaviour that challenges (DH, 2007). Challenging behaviour should be viewed as a social construct and as such, has parallels with hearing loss. Though it is often viewed as maladaptive, Kevan (2003) argues that challenging behaviour is actually adaptive and communicative and used if a more acceptable form of communication is unavailable (for example, due to undetected hearing loss). A consequence of hearing loss is difficulty in accessing receptive language, and studies have demonstrated a correlation between receptive language deficits and challenging behaviour (Kevan, 2003; Sigafoos, 2000).

Obviously, not every individual with challenging behaviour will have a hearing loss and vice versa. However, there is an association between sensory loss and challenging behaviour in people with intellectual disabilities (Timehin & Timehin, 2004). The literature has examples of the use of hearing aids in reducing challenging behaviour (McShea et al, 2014).

7. Multidisciplinary Approach

The purpose of the multidisciplinary team (MDT) is to bring relevant professionals together to improve audiological issues for people with intellectual disabilities, by working across traditional professional boundaries. As Hills et al (2007) describe, this meeting allows professionals to reflect on previous practice, engage in critical dialogue and develop future insight. This holistic approach is particularly important when working with clients with profound and multiple intellectual disabilities (PMID). Please see BSA Guidance Audiological Assessment for Adults with Intellectual Disabilities and Access to Audiology Services for Adults with Intellectual Disabilities for further information.

Appendix 1: Accessible Reports and Appointment Letters

Date

Dear

Photo of staff member

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

Photo of staff member

Signature

Audiologist

HEARING AID CLOSURE REPORT

Name: Address:

Photo of staff member

I came to see you at home on _____. Your carer, _____ was with you.

You told me about your new hearing.

You got your new hearing at Hospital.

Your told me that when you wear your hearing aid your hearing is good.

You showed me how you use your hearing aid.
You showed me how you clean your hearing aid.

We agreed that you use your hearing aid very well.

When you need more batteries, you can telephone or visit

If your hearing aid does not work you can telephone the hospital for an appointment to have it fixed.

We agreed that I did not need to see you anymore.
I have closed your file.

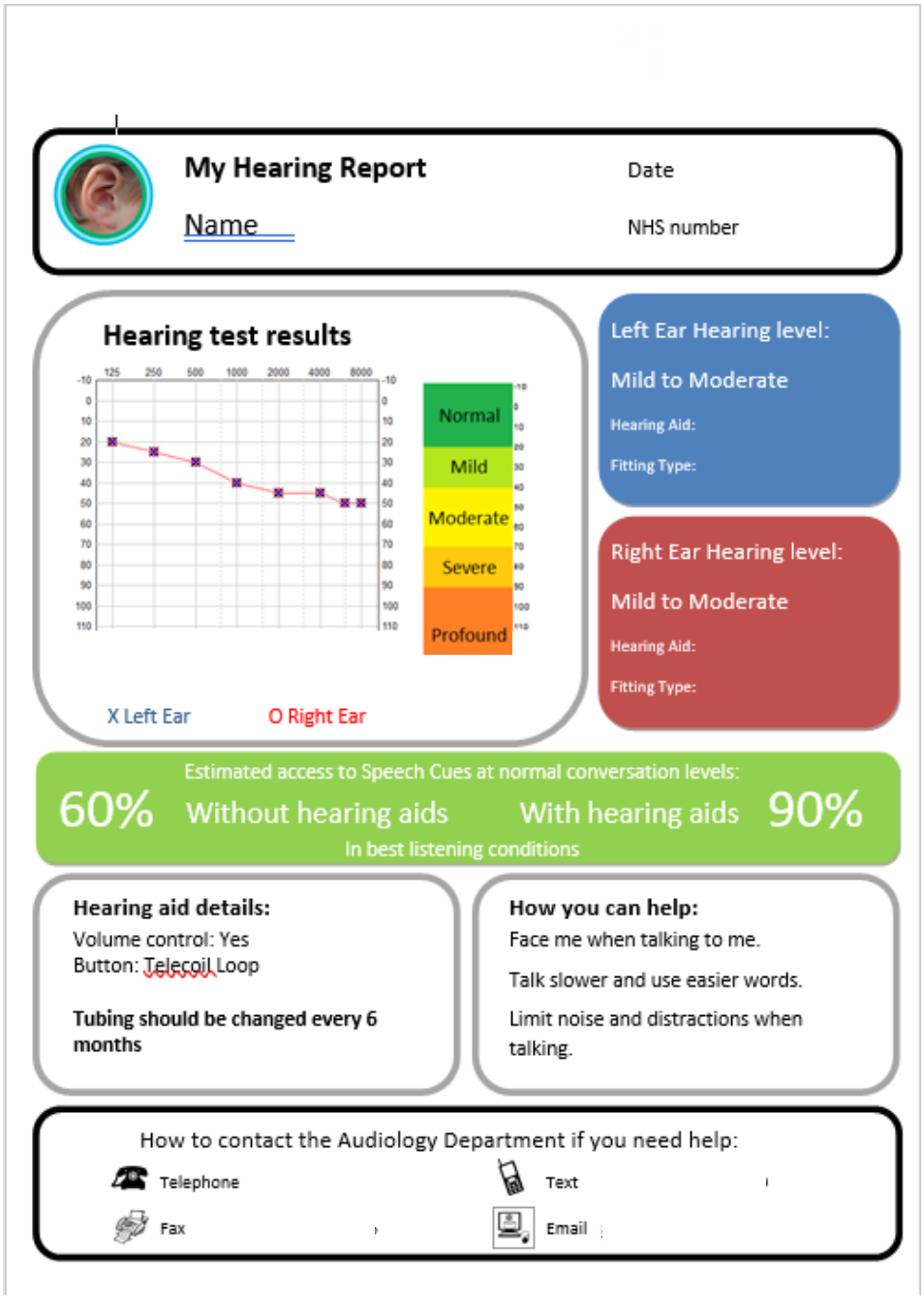
You can telephone me if you are worried about your ears on

Photo of staff member

Signature
Audiologist

Date:

2


My Hearing Report
Date
Name
NHS number
Hearing test results
125 250 500 1000 2000 4000 8000
Normal
Mild
Moderate
Severe
Profound
X Left Ear
O Right Ear
Left Ear Hearing level:
Mild to Moderate
Hearing Aid:
Fitting Type:
Right Ear Hearing level:
Mild to Moderate
Hearing Aid:
Fitting Type:
Estimated access to Speech Cues at normal conversation levels:
60%
Without hearing aids
With hearing aids
90%
In best listening conditions
Hearing aid details:
Volume control: Yes
Button: Telecoil Loop
Tubing should be changed every 6 months
How you can help:
Face me when talking to me.
Talk slower and use easier words.
Limit noise and distractions when talking.
How to contact the Audiology Department if you need help:
Telephone
Text
Fax
Email

AUDIOLOGY REPORT

Name: Address:

I came to see you at home on the

I looked in your ears

I tested your hearing

Your hearing is good

I will write to your doctor to tell them

You can telephone me if you are worried about your ears at

Audiologist Date:

SPECIALIST AUDIOLOGY SERVICE FOR ADULTS WITH LEARNING DISABILITIES

LISTENING DIARY

Week Beginning .....

Name

ACTIVITY	HEARING AID IN	HEARING AID OUT			COMMENTS
 AROMATHERAPY					
 EXERCISE CLASS					
 GATEWAY CLUB					
 KNITTING					

Appendix 2: Carer Training Summary

NHS
Guy's and St Thomas'
NHS Foundation Trust

Community Learning Disability Health Team
Specialist Audiology Services for AWLD

HEARING PROBLEMS AND SOLUTIONS

AIM
To provide participants with knowledge and insight into the nature of hearing impairment for people with a learning disability, and provide skill training in hearing aid maintenance and communication tactics.

LEARNING OUTCOMES
Participants should be able to:
1. Identify the main causes of hearing loss in adults with learning disability.
2. Understand the effects of hearing loss on the client's ability to communicate and use appropriate communication methods.
3. Give a basic explanation of the assessment process and their role within it.
4. Provide basic maintenance to a hearing aid.
5. Contact providers about resources and information available for the hearing impaired, in particular around environmental aids.
6. Make a referral to the Specialist Audiology Service.

COURSE DURATION: 1 day

TARGET GROUP: Support staff, carers and professionals currently working with AWLD and a known or suspected hearing impairment.

COURSE CONTENT
The course is divided into 6 areas:
- Experience of hearing loss
- Effects of hearing loss on communication
- Causes of hearing impairment
- Assessment of hearing loss in adults with learning disability
- Hearing aid maintenance
- Alternative methods of supporting clients with a hearing impairment

NHS
Guy's and St Thomas'
NHS Foundation Trust

Community Learning Disability Health Team
Specialist Audiology Services for AWLD

HEARING AID WORKSHOP

AIM
To provide participants with the knowledge and skills to support a client to use a hearing aid by providing basic maintenance and simple repairs.

LEARNING OUTCOMES
Participants should be able to:

- Identify different types of hearing aids
- Identify left and right ~~earmoulds~~
- Insert an ~~earmould~~ into the ear
- Use hearing aid controls
- Clean a hearing aid
- Replace a hearing aid battery
- ~~Retube~~ a hearing aid
- Carry out simple fault finding and repairs

TARGET GROUP
Support staff, carers and professionals currently working with adults with learning disabilities using or about to use a hearing aid.

COURSE CONTENT
The course will be an experiential workshop covering:

- Hearing aid identification
- Hearing aid maintenance
- Basic hearing aid repair

COURSE 2 hours

Appendix 3: Audiological Care for AWID Evaluation Toolkit

Aim	Met	Partially Met	Not Met	Action Plan if required
Staff have training in working with adults with learning disabilities. This should include the Mental Capacity Act Code of Practice, optimising communication techniques and specialist knowledge of factors relating to intellectual disabilities that may influence Audiological care				
Staff work in a person-centered way and for each client become familiar with their person-centred information such as a hospital passport.				
Efforts are be made to identify the clients' priorities for their sensory input				
Staff enable clients to have continuity of care as far as is reasonably possible.				
Input is gained from a client's Key Worker and/or close family regarding optimising hearing assessment and rehabilitation as appropriate				
Staff regularly provide opportunities for difficulties that clients may be having to be identified				
Staff show evidence of providing as easily accessible information about hearing assessments and rehabilitation in a range of formats.				
Staff provide clients with information as appropriate regarding improving ear health and reducing noise exposure				
Staff reduce barriers to access to Audiology services as far as possible. A pathway to specialist Audiological care is available				
Staff provide Audiological care in a range of accessible locations including the clients' homes and day services for clients who find attending a hospital setting prohibitive				
Staff work closely with approrpriate multidisciplinary professionals including community learning disability teams and other health professionals to improve Audiological care for their clients				

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