

Audiology Services: Provision for People with Intellectual Disabilities and Autistic People

Please complete these questions if your audiology service provides diagnostic hearing assessments AND hearing aid provision for people with intellectual disabilities and/or autistic people. This provision may be delivered through a specialist service or as part of your mainstream service.

For the purpose of this request the following terms have been used:

Intellectual Disabilities: People who have an intellectual or learning disability identified in their medical records.

Autistic People: People who have autism spectrum disorder and whose autism is known to audiology services.

Co-occurrence of intellectual disabilities and autism: Autism spectrum disorder is not an intellectual disability, but these conditions may co-occur. For the purposes of these questions, questions which ask for information regarding autistic people refer to autistic people without an intellectual disability. Where autism co-occurs with an intellectual disability, please include these people in the information regarding intellectual disabilities.

Clinical definitions of intellectual disabilities and autism are included in the footnote.

Scope: This information request **does not** include services for people with specific learning difficulties, such as dyslexia, or later acquired cognitive deficits, such as dementia.

Please base your answers on your service provision between 1st May 2021 and 31st July 2021.

The vast majority of these questions can be answered with a “Select all that apply” or yes/no choice

Intellectual Disabilities: intellectual disability is defined according to the World Health Organization 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.”

Autism: The term “autistic people” is used to refer to any individual with autism spectrum disorder. According to the World Health Organization, autism spectrum disorder is “characterised by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensation”.

Section 1: Your service

Please answer the questions below based on the situation as of July 2021.

Your name:	Jane Deans
Your role:	Head of Audiology
Your email address:	Jane.deans@wales.nhs.uk
Your telephone number:	01267 227449

Please give the name of your audiology service/s. If you provide services on behalf of another Trust/s please provide details of all the Trusts that you provide services for below. **Please write names in full and expand acronyms:**

Hywel Dda University Health Board (UHB) Audiology Department

Section 2: Your caseload of people with intellectual disabilities and autistic people

2.1 Does your hospital or audiology service have a mechanism for identifying and flagging people with intellectual disabilities who use the service?

Yes	X
-----	---

No	
----	--

If yes, please specify how you store and use this information?

Set as an 'alert' on our patient management system - AuditBase

2.2 Does your hospital or audiology service have a mechanism for identifying and flagging autistic people who use the service?

Yes	X
-----	---

No	
----	--

If yes, please specify how you store and use this information?

Set as an 'alert' on our patient management system - AuditBase

Please include the following information for your service. **We understand that you may not record all these numbers.** Please only fill in the numbers your service records or provide an estimate if possible (noting with an E). If you do not record these numbers and cannot make a reasonable estimate, please state 'not recorded':

Total population of the area that your service covers	387,500 (E)
The geographical boundaries your service covers	Carmarthenshire, Pembrokeshire and Ceredigion
Age group your service covers (e.g., 0 – 18 years, 18+ years)	0 – 18 and 18+
Total number of adults with intellectual disabilities who were seen between 1st May and 31st July 2021.	Not recorded
Total number of children (<18 years) with intellectual disabilities who were seen between 1st May and 31st July 2021.	Not recorded
Total number of autistic adults who were seen between 1st May and 31st July 2021.	Not recorded
Total number of autistic children (<18 years) who were seen between 1st May and 31st July 2021.	Not recorded

Section 3: Transition to adult services

3.1 How do you prepare young people with intellectual disabilities and/or autistic young people for transition to adult services? Please select all that apply.

Not applicable: adult only service	Not applicable
Provide easy read information on the adult service for young people	No
Professional liaison arranged between adult and paediatric services prior to transition	Yes
Offer an appointment with the adult service before being discharged from the children's service	Yes – Transition clinics
Hold joint appointments with both paediatric and adult audiologist present	Yes – if required
Visit local schools to offer sessions to share information with young people about deafness, independence and transition etc.	No
Discuss reasonable adjustments that can be offered in the adult service	Yes
None of the above	

Other please state:

--

Section 4: Reasonable Adjustments

Reasonable adjustments: According to The Equality Act 2010, service providers should make ‘reasonable adjustments’ to their provision, to allow disabled people to access the same services as non-disabled people. These adjustments will be different for different services. What is reasonable for one provider may not be possible or relevant for another provider.

4.1 Do you make any of the following reasonable adjustments to facilitate accessibility to audiology services? Select all that apply:

	For people with intellectual disabilities	For autistic people	For anyone who needs them
Test room of sufficient size to accommodate client, up to 2 carers and up to 2 testers	Yes – if required	Yes – if required	Yes – if required
Wheelchair access	Yes	Yes	Yes
Directions to your service written in an accessible format and clear signage displayed <i>in situ</i>	Yes	Yes	Yes
A quiet waiting area	Removed due to COVID-19	Removed due to COVID-19	Removed due to COVID-19
An appropriate alternative to a soundproof room for patients who find this unpleasant	Yes	Yes	Yes
Range of testing position options within test room	Yes – room layout can be adjusted if required	Yes – room layout can be adjusted if required	Yes – room layout can be adjusted if required
Home visit	Yes. However only if housebound	Yes. However only if housebound	Yes. However only if housebound
Appointments at Day Services or Day Centres	No	No	No

Other – please specify:

4.2 Do you make any of the following reasonable adjustments to facilitate appointment flexibility? Select all that apply:

	For people with intellectual disabilities	For autistic people	For anyone who needs them
Longer appointment times	Yes	Yes	Yes – if highlighted by clinician
Providing breaks during appointments or offering multiple appointments	Multiple appointments	Multiple appointments	Multiple appointments
Option of different times	Yes	Yes	Yes
Extended opening times (before 9 am and/or after 5pm)	Yes	Yes	Yes
Saturday appointments	No	No	No
Telephone or video appointments	Yes	Yes	Yes
We offer extra appointments in school holidays	No	No	No
We deliver some services in schools and/or community settings	No	No	No

Other – please specify:

4.3 Do you make any of the following reasonable adjustments to testing procedures? Select all that apply:

Soundfield behavioural testing in addition to ear-specific testing	Yes
Visual reinforcement audiometry or behavioural observation audiometry for adults	Yes – if required, via Paediatric Team
Electrophysiological assessment in an outpatient setting	Yes
Electrophysiological assessment under sedation or general anaesthetic	Yes

Other – please specify:

4.4 What attempts are made to find out what the individual's needs are prior to the appointment (e.g., communication, physical, behavioural needs)?

Check referral letter	Yes
Check hospital records	Yes – if further information required
Contact patient	Not as standard
Contact family/key workers (as appropriate)	Not as standard

Other – please specify:

4.5 Do you make any of the following reasonable adjustments to facilitate communication? Select all that apply:

Ability to book communication support professionals where necessary (e.g., interpreters, speech-to-text reporters, lipspeakers)	Yes
Range of options for contacting the service (e.g., email, mobile number with text option)	Yes
Easy read versions of appointment letters	Yes
Easy read versions of patient letters and reports of findings	Available if required

Other – please specify:

4.6 Do you make any of the following reasonable adjustments to providing patient information? Select all that apply:

Easy read patient information	Available if required
Pictorial resources explaining processes in clinic e.g., audiology	No
Video information about the department, staff and appointment	No

Other – please specify:

4.7 Do you currently provide a choice of coloured moulds to people with intellectual disabilities and/or autistic people at no extra charge? Please select one answer:

Yes, always	<input checked="" type="checkbox"/>
-------------	-------------------------------------

No, never	<input type="checkbox"/>
-----------	--------------------------

Yes, with limitations – please specify:

4.8 Does your service offer any of the following adaptions people with intellectual disabilities and/or autistic people?

	For people with intellectual disabilities	For autistic people	For anyone who needs them
Hearing aid fittings with 2 members of staff	No	No	No
Speech testing to evaluate outcome	Yes	Yes	Yes
Soundfield Aided thresholds	Yes	Yes	Yes
RECD	Yes	Yes	Yes
Additional follow-up review appointments to support acclimatisation / adaptation to amplification	Yes	Yes	Yes
Training for carers and families on hearing aid use	Only as part of fitting appointment	Only as part of fitting appointment	Only as part of fitting appointment
Training for carers and families on communication	No	No	No
Easy read care plans	Can be obtained if required	Can be obtained if required	Can be obtained if required
Easy read information on hearing aid use	Can be obtained if required	Can be obtained if required	Can be obtained if required
Home visits to evaluate hearing aid use in a domestic setting	No	No	No

Section 5: Wax management

5.1 How is problematic wax managed in people with intellectual disabilities and/or autistic people in your service? Select all that apply:

Advice issued re drops	Yes
Referral to GP surgery	No
Referral to mainstream ENT services	Yes – if required
Referral to ENT services with specialist skills re. people with intellectual disabilities	Not applicable
Removal within Audiology clinic by Audiology staff	Yes
Information about ear wax (risks, side effects, management etc.) offered in a range of formats (e.g., Easy Read).	Can be obtained if required

Other – please specify:

Section 6: Specialist Services

Specialist Services: By specialist services, we mean audiological services which are provided separately from your mainstream provision, specialised for people with intellectual disabilities and/or autistic people. This might mean an entirely separate service for these groups, or the opportunity to be seen by professionals who specialise in working with these groups, in a mainstream setting.

6.1 Of the people with intellectual disabilities and autistic people that you saw between 1st May and 31st July 2021, how many were seen by a specialist service as opposed to your mainstream service (please give a number for all that apply)? **We understand that you may not record these numbers.** If you do not record these numbers and cannot make a reasonable estimate, please state 'not recorded':

	For people with intellectual disabilities	For autistic people
Specialist audiology service for people with complex needs	Not recorded	Not recorded
Mainstream audiology services	Not recorded	Not recorded
Mixture of mainstream and specialist service	Not recorded	Not recorded

6.2 Of the people with intellectual disabilities and autistic people that you saw between 1st May and 31st July 2021, what review processes were available (please select all that apply)?

	For people with intellectual disabilities	For autistic people
Normal hearing – discharge, self-referral to return	Yes	Yes
Normal hearing – routine review	No	No
Hearing Loss – same review as mainstream service	Based on clinical judgement	Based on clinical judgement
Hearing Loss – additional review appointments	If required	If required

6.3 Of the people with intellectual disabilities and/or autistic people that you saw between 1st May and 31st July 2021, how many were offered the following services (please give a number for all that apply). **We understand that you may not record these numbers.** If you do not record these numbers and cannot make a reasonable estimate, please state 'not recorded':

	For people with intellectual disabilities	For autistic people
Hearing Therapy	Not recorded	Not recorded
Vestibular assessment or rehabilitation	Not recorded	Not recorded
ENT	Not recorded	Not recorded
Cochlear Implant Services	Not recorded	Not recorded
Tinnitus assessment or rehabilitation	Not recorded	Not recorded
Sensory teams	Not recorded	Not recorded
Other Implantable Devices	Not recorded	Not recorded

Other – please specify:

Section 7: Meeting Relevant Guidance

7.1 How closely do you work to the following relevant guidance?

	Awareness	Implement in part	Implement in full	Not heard of
Learning Disabilities Improvement Standards for NHS Trusts https://improvement.nhs.uk/documents/2926/v1.17_Improvement_Standards_added_note.pdf	X			
PMLD Service Standards: http://www.thesensoryprojects.co.uk/PMLD-service-standards				X
The Accessible Information Standard https://www.england.nhs.uk/ourwork/accessibleinfo/			All Wales Standards for Accessible Communication and Information for People with Sensory Loss	
British Society of Audiology Practice Guidance for Adults with Intellectual Disabilities https://www.thebsa.org.uk/resources/access-to-audiology-services-for-adults-with-intellectual-disabilities/		X		

Section 8: Your policies

8.1 What documentation do you currently have specific to people with intellectual disabilities and autistic people? Select all that apply and indicate whether 'in place' or 'in progress'. These documents may be trust/hospital-specific or may be specific to your department/service.

	In place	In progress
Patient Pathway(s)	Yes	
Audiology-specific SOPs that refer to working with people with intellectual disabilities	Yes	
Audiology-specific SOPs that refer to working with autistic people	Yes (as part of above document)	

Training logs relevant to staff skills on working with people with intellectual disabilities		No
Training logs relevant to staff skills on working with autistic people		No
Risk Assessments (detail in question 9.2)		Yes
Transition SOPs or policy	Yes	
Other – please specify:		

8.2 Do you carry out the following risk assessments? Select all that apply:

	Formal risk assessment	Informal risk assessment (risk identified and recorded in medical notes)
Challenging Behaviour		Yes
Risks of inaccuracy of behavioural assessment		Yes
Risk associated with communication barriers		Yes
Discharging without ear-specific information		Yes
Lack of sufficient support with hearing aid use		Yes
Lack of equal access to services for people with intellectual disabilities		Yes

Other, please specify:

--

8.3 How does your ‘Did Not Attend’ policy differ for people with intellectual disabilities and/or autistic people to that of the wider patient population?

Did Not Attend / Was Not Brought letters are sent to both the patient (or carer) and GP and recorded in the patient management system (AuditBase)

Section 9: Referral Routes

9.1 Of the new referrals of people with intellectual disabilities and autistic people, that you received between 1st May and 31st July 2021, where did the referrals originate from? Please select all that apply.

GP	Yes
Community Learning Disabilities Team	Yes
ENT	Yes
Paediatric Audiology Services	Yes
Newborn Hearing Screen	Yes
Out-of-area Audiology Service	No

Speech and Language Therapy	Yes
School nursing team	Yes
Community Paediatric team	Yes
Hearing screening pathway for adults or children with intellectual disabilities	No
Annual Health Check	No
Other	

Other: (please specify)

Section 10: Multidisciplinary Working

10.1 Of the people with intellectual disabilities that you saw between 1st May and 31st July 2021, how often did you make referrals to the following professionals when they are required. Please select all that apply and indicate estimate of frequency of referral.

	Always	Often	Sometimes	Rarely	Never
Speech and Language Therapy					Policy is that the patient would need to be referred back to their GP for onward management / referral
Community Learning Disabilities Team					Policy is that the patient would need to be referred back to their GP for onward management / referral

Teacher of the Deaf			X – based on age		
Ear, Nose and Throat			X		
Occupational Therapy					Policy is that the patient would need to be referred back to their GP for onward management / referral
Other					

10.2 Of the autistic people that you saw between 1st May and 31st July 2021, how often did you make referrals to the following professionals when they are required. Please select all that apply

	Always	Often	Sometimes	Rarely	Never
Speech and Language Therapy					Policy is that the patient would need to be referred back to their GP for onward management / referral
Community Learning Disabilities Team					Policy is that the patient would need to be referred back to their GP for onward

					management / referral
Teacher of the Deaf			X – based on age		
Ear, Nose and Throat			x		
Occupational Therapy					Policy is that the patient would need to be referred back to their GP for onward management / referral
Other					

10.3 Do you have access to any of the following? Select all that apply:

Employer policies on working with people with intellectual disabilities	No
Employer policies on working with autistic people	No
Employer-provided training on working with people with intellectual disabilities	No
Employer-provided training on working with autistic people	No
Employer involvement in the Mencap Treat Me Well Campaign	No
Effective links to other professionals with specialisms in working with people with intellectual disabilities and/or autistic people	No

Section 11: Staffing and Training

11.1 Are the staff (e.g., audiologists, receptionists) in your service able to access the CPD necessary for working with people with intellectual disabilities and/or autistic people?

All staff	Yes (via ESR)
Some staff	

None	
------	--

If CPD is not available for all staff in your service, necessary for working with people with intellectual disabilities and/or autistic people, please indicate why not (select all that apply):

Financial constraints	
Training expenses are not covered e.g., travel to training	
No cover for clinical duties	
Other: please specify	

11.2 If you offer a specialist service for people with intellectual disabilities and/or autistic people, how many full-time equivalent staff were routinely involved on 31st July 2021? (Please select all that apply). Specialist provision can include an entirely separate service for these groups, or the opportunity to be seen by professionals who specialise in working with these groups, in a mainstream setting. Please express part-time roles as a fraction of a full-time role e.g., 1 full-time role and a part-time role of 3 days would be 1.6 FTE.

Level	Permanent posts	Locum/ temporary posts	Trainees
Band 1			
Band 2			
Band 3			
Band 4			
Band 5			
Band 6			
Band 7	1.84 Whole Time Equivalent (WTE) – Adults 8.4 WTE - Paediatrics		
Band 8 a	1 WTE- Paediatrics		
Band 8 b			
Band 8 c			

Band 8 d			
Band 9			
Doctor specialising in audiology (paediatrician, audio vestibular physician etc)			
Other staff e.g., Volunteers and students			

11.3 What training have the staff in your service been offered for working with people with intellectual disabilities and/or autistic people? (Please select all that apply)

	Clinical staff working in a specialist audiology service for people with intellectual disabilities and/or autistic people	Clinical staff who work with people with intellectual disabilities and/or autistic people in a mainstream audiology service	Non-clinical staff who work in the audiology service (e.g., receptionist, porter)
Mental Capacity Act training	Yes	Yes	Yes
Communication training (relevant to those with intellectual disabilities e.g., Makaton etc)	No	No	No
Learning Disability Awareness	Available; however not mandatory	Available; however not mandatory	Available; however not mandatory
Autism Awareness	Available; however not mandatory	Available; however not mandatory	Available; however not mandatory
Shadowing specialist clinics	No	No	No
Accessible Information Standard Training	No	No	No
Generic Violence and Aggression Training	Yes	Yes	Yes
Challenging Behaviour	Yes	Yes	Yes
Other, please detail:			

Section 12: Patient engagement and service evaluation

Please answer the questions in this section based on the situation as of 31st July 2021.

12.1 What patient feedback mechanisms do you have in place for services for people with intellectual disabilities and/or autistic people?

None – unless completed on generic feedback forms

What have been the most recent outcomes of patient feedback regarding services for people with intellectual disabilities and/or autistic people?

Not applicable

12.2 Do you audit/evaluate your service practices for people with intellectual disabilities and/or autistic people? Please give a brief explanation (1 or 2 sentences).

Yes (please specify how)	
No (please specify why)	Not currently in place. However, will be implemented when the All Wales Quality Standards are amended to include patients with intellectual disabilities and/or autistic people

12.3 Are there any aspects of service delivery that you adapted during the Coronavirus pandemic, which you intend to retain beyond the end of restrictions (e.g., tele-audiology, telephone reviews)? Please give brief details and an explanation of why.

Telephone follow ups – to minimise footfall in hospital locations and for people to be in a ‘safe’ environment

Attend Anywhere - to minimise footfall in hospital locations and for people to be in a ‘safe’ environment

Assess and fit – to minimise the number of times patients were required to come to hospital. Only offered if the patient has the ability to retain information for longer periods of time. If not, a fitting appointment is booked.

12.6 Are there plans to develop your service for people with intellectual disabilities and autistic people in the near future? Please give a brief description of any planned changes.

Yes – to become more in line with both professional and health board best practice.

If you would like to discuss audiological provision for people with intellectual disabilities and autistic people further please consult the Audiology, Learning Disability and Autism Project (ALDAP) study website: <https://sites.manchester.ac.uk/aldap/> or contact the research team:

Siobhan Brennan, Marianne Day, Shanice Thomas

Email: Siobhan.brennan@manchester.ac.uk

Telephone: 07917605544

Division of Human Communication, Development and Hearing

Address: Ellen Wilkinson Building, University of Manchester, M15 6JA

Amanda Hall

Email: a.hall@aston.ac.uk

Audiology Lecturer, Life and Health Sciences

Aston University, Aston St, Birmingham B4 7ET

Many thanks for your time.