

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

Please complete this survey 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 this survey, 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:	J F Grant
Your role:	Head of Audiology Services
Your email address:	Jane.grant@mkuh.nhs.uk
Your telephone number:	01908 995325

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:**

Audiology Services, Milton Keynes University Hospital NHS Foundation Trust

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	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>
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If yes, please specify how you store and use this information?

We have an alert on Auditbase for Learning Disability (longstanding terminology) , which is set by Audiology when we receive a new referral for a patient identified with intellectual disability. This enables us to identify the patients who may need reasonable adjustments to ensure the service is accessible eg book appropriate appointments for them and send them ' easy read' information as appropriate.

The trust has an Electronic Patient Record (EPR) and within this clinicians are able to record Flag/Alerts for patients to highlight specific criteria to other staff. This Flag/Alert can be based on a Diagnosis or a finding using SNOMED CT. A Flag/Alert can be added for many reasons including Learning Disabilities or Reasonable Adjustments for health and care access.

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

Yes	<input checked="" type="checkbox"/>	No	<input type="checkbox"/>
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If yes, please specify how you store and use this information?

We have an alert on Auditbase that identifies patients with specific audiological needs. We set this alert for patients with autism identified either at referral stage, during complex phone calls prior to an appointment, or during an appointment. This enables us to tailor the appointment to the specific needs of the patient. As the alert includes other audiological factors we cannot break down specific numbers of patients with autism.

There is also an autism parameter which aids this identification

The trust has an Electronic Patient Record (EPR) and within this clinicians are able to record Flag/Alerts for patients to highlight specific criteria to other staff. This Flag/Alert can be based on a Diagnosis for example Autism or, if no diagnosis has been confirmed Reasonable Adjustments for health and care access Flag/Alert can be used.

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	Not recorded
The geographical boundaries your service covers	Not recorded
Age group your service covers (e.g., 0 – 18 years, 18+ years)	All ages
Total number of adults with intellectual disabilities who were seen between 1st May and 31st July 2021.	30 appointments
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	
Provide easy read information on the adult service for young people	Yes
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

Hold joint appointments with both paediatric and adult audiologist present	Yes
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:

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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	Yes	Yes
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	No	No	No
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	Yes	Yes
Home visit	On occasion	No	Limited
Appointments at Day Services or Day Centres	No	No	No

Other – please specify:

We would consider home visits for autistic patients but have not been required to do this so far.

Although we do not have a quiet waiting area, patients needing a quiet area are usually given the first appointment in the clinic when the waiting room is quiet, and taken straight into the clinic room.

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
Providing breaks during appointments or offering multiple appointments	Yes	Yes	Yes

Option of different times	Yes	Yes	Yes
Extended opening times (before 9 am and/or after 5pm)	Not routinely	Children offered prior to 9am	Not routinely
Saturday appointments	No	No	No
Telephone or video appointments	Not generally offered	Yes – see note	Not generally offered
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:

Telephone appointments (complex call appointment) are undertaken with families of autistic children prior to the appointment.

For adults with intellectual disability, history is usually taken over the phone to allow a suitable appointment to be booked and identify testing needs. Adult hearing aid reviews may also be done over the phone.

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
Electrophysiological assessment in an outpatient setting	Yes
Electrophysiological assessment under sedation or general anaesthetic	Yes

Other – please specify:

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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
Contact patient	Yes
Contact family/key workers (as appropriate)	Yes

Other – please specify:

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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	Yes

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	Yes
Pictorial resources explaining processes in clinic e.g., audiometry	Yes
Video information about the department, staff and appointment	Yes

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	Yes	No, never	
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Yes, with limitations – please specify:

4.8 Does your service offer any of the following adaptations 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	Yes	Yes	Yes

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	Yes	Yes	Yes
Training for carers and families on communication	Yes	Yes	Yes
Easy read care plans	Yes	Yes	Yes
Easy read information on hearing aid use	Yes	Yes	Yes
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	Yes
Referral to mainstream ENT services	Yes
Referral to ENT services with specialist skills re. people with intellectual disabilities	No
Removal within Audiology clinic by Audiology staff	No
Information about ear wax (risks, side effects, management etc.) offered in a range of formats (e.g., Easy Read).	No

Other – please specify:

We have information in easy read format on the use of olive oil for ear wax.

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
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Specialist audiology service for people with complex needs	30 adult appointments	Not recorded
Mainstream audiology services	Not recorded	Not recorded
Mixture of mainstream and specialist service		

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	No	No
Normal hearing – routine review	Yes	No
Hearing Loss – same review as mainstream service	Yes	Yes
Hearing Loss – additional review appointments	Yes if required	Yes 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 offered	Not offered
Vestibular assessment or rehabilitation	Not offered	Not offered
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:

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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/			X	
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)	X	
Audiology-specific SOPs that refer to working with people with intellectual disabilities	X	
Audiology-specific SOPs that refer to working with autistic people	X	
Training logs relevant to staff skills on working with people with intellectual disabilities		
Training logs relevant to staff skills on working with autistic people		
Risk Assessments (detail in question 9.2)		
Transition SOPs or policy	X	

Other – please specify:

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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		N/A

Other, please specify:

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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?

There may be multiple attempts to contact the patient/family to re-appoint.

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	X
Community Learning Disabilities Team	
ENT	
Paediatric Audiology Services	
Newborn Hearing Screen	
Out-of-area Audiology Service	
Speech and Language Therapy	
School nursing team	
Community Paediatric team	
Hearing screening pathway for adults or children with intellectual disabilities	
Annual Health Check	
Other	

Other: (please specify)

Adult referral came from GP. Too time consuming to trawl through all referrals for children.

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					X
Community Learning Disabilities Team				X	
Teacher of the Deaf	X				
Ear, Nose and Throat	X				
Occupational Therapy					X
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					X
Community Learning Disabilities Team					X
Teacher of the Deaf	X				
Ear, Nose and Throat	X				
Occupational Therapy					X
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	
Employer policies on working with autistic people	
Employer-provided training on working with people with intellectual disabilities	X
Employer-provided training on working with autistic people	X
Employer involvement in the Mencap Treat Me Well Campaign	
Effective links to other professionals with specialisms in working with people with intellectual disabilities and/or autistic people	X

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 for Audiology staff
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

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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	2 – unable to break down equivalent WTE working in this specific area		
Band 7	2 – unable to break down equivalent WTE working in this specific area		
Band 8 a			
Band 8b	1– unable to break down equivalent WTE working in this area		
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
Communication training (relevant to those with intellectual disabilities e.g., Makaton etc)			
Learning Disability Awareness		Yes	Yes

Autism Awareness		Yes	No
Shadowing specialist clinics			
Accessible Information Standard Training			
Generic Violence and Aggression Training			
Challenging Behaviour		Yes	Yes

Other, please detail:

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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?

Friends and Family responses

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

Anecdotally complex call phone calls very well received.

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)	Adult learning disability service is audited to check patients have been offered a review appointment.
No (please specify why)	

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.

Use of phone reviews in Adult Learning Disability Service was already in practice before the pandemic

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.

Plans to review some of the Easy Read literature.