

Improving Hearing Services for People with Learning Disabilities

Participant Information Sheet

You are being invited to take part in a research study which aims to understand the challenges and barriers that people with learning disabilities face when they access Hearing Services (Audiology) or attempt to access Hearing Services. Before you decide to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➤ **Who will conduct the research?**

This project is being led by Dr. Siobhan Brennan at the University of Manchester. **Siobhan has worked as an Audiologist in Sheffield, Chesterfield, Barnsley and Rotherham.** Focus groups will be carried out by Marianne Day, Siobhan Brennan, or Shanice Thomas. All members of the research team are based in the Division of Human Communication, Development and Hearing at the University of Manchester. The project is being run in collaboration with Health Education England (South East Region).

➤ **What is the purpose of the research?**

The NHS have recognised that healthcare, including Hearing Services (Audiology), need to be improved for people with learning disabilities. People with learning disabilities and autistic people are more likely to have undiagnosed and untreated hearing loss. If hearing loss is not identified or addressed, this can impact on a person's quality of life,

Improving Hearing Services for People with Learning Disabilities

behaviour, and ability to communicate. This study aims to identify the challenges and barriers people with learning disabilities face when they access Hearing Services (Audiology) or try to access Hearing Services. The findings will be used to provide guidance and recommendations for Hearing Service providers about how to improve their services.

You have been approached to take part in this study because you have a learning disability, or you are a caregiver or carer of a person with learning disabilities. We want to include people with learning disabilities who have used hearing services, and those who wanted to use these services but were unable to. We want to recruit around 18 adults with learning disabilities and 18 families of children with learning disabilities, to take part in six different focus groups.

➤ **Will the outcomes of the research be published?**

We will share what we find out about the challenges of accessing Hearing Services (Audiology) with Health Education England, with Hearing Service providers, and with people with learning disabilities and their support organisations. We will write journal articles and presentations for other academics and stakeholders who are interested in this area.

We will also share our findings on the study website (<https://sites.manchester.ac.uk/aldap/>). If you give your consent to take part, you can choose to receive a summary of what we found at the end of the project. The summary of the research findings will be provided in a format that is suitable for you.

➤ **Disclosure and Barring Service (DBS) Check**

The researchers have all undergone an enhanced level of DBS check (Disclosure and Barring Service) which checks their suitability to work with children and vulnerable groups.

➤ **Who has reviewed the research project?**

This project has been reviewed and approved by The University of Manchester Research Ethics Committee (ref: 2021-11556-19992).

➤ **Who is funding the research project?**

This project is being funded by Health Education England, which is part of the NHS in England.

What would my involvement be?

➤ What would I be asked to do if I took part?

If you give consent to take part in the study, you will be asked to attend one focus group. Face-to-face focus groups will be held once Coronavirus restrictions are lifted, and it is safe to hold a meeting indoors. The venue for these will be (*community group setting/school will be written here once confirmed*) and will be arranged at a time which is convenient to you. Focus groups will include 4-6 people with a learning disability, and/or a caregiver/parent/carer (as appropriate). The focus groups will be led by at least two members of the research team (Siobhan Brennan, Marianne Day, Shanice Thomas). The focus groups will be around one hour long and will be recorded using a password-protected University of Manchester iPad or laptop.

During the focus group, we will ask questions about your experiences of accessing Audiology (Hearing) services, either for yourself, or on behalf of a person with learning disabilities. These are the main questions we will ask:

- What audiology provision have you had (hearing test, appointments, received information from audiology, hearing management, such as hearing aids)?
- Where did you receive this provision (e.g., hospital, high street provider)?
- How did you find accessing Hearing Services (was it good/bad, easy, stressful, confusing)?
- What went well with these services?
- Were there things that did not go well?
- Do you have any recommendations or advice for hearing professionals about how they could improve their services?

Improving Hearing Services for People with Learning Disabilities

You do not need to tell us anything you do not want to. You do not have to explain the diagnoses or treatments you have had. We will only ask about your experiences of accessing Hearing Services. We would encourage participants not to name specific audiologists or clinics, where possible. We will also remove all identifying information about hearing service providers from the final transcripts.

We will show you some materials that Hearing Services use to communicate with people with learning disabilities. We would like to know what you think of these materials and whether you think they could be better.

➤ **Risks**

It is unlikely that you will experience distress during the focus group. However, it is possible that this could happen. We can pause or discontinue the focus group if required. You are free to leave at any time if you do not feel comfortable. You do not have to tell the researcher why you want to leave. You also do not have to answer any question you do not want to answer.

➤ **Preparing for the Focus Group**

We understand that people have different communication, sensory, and behavioural needs. We will plan the focus groups so that everyone is able to give their views. The research team will arrange to speak with you (and, if appropriate, a family member or caregiver) before the focus group takes place, to discuss your needs and preferences. Please tell us what adjustments we can make to help you participate in the focus group. We will provide information in different formats, for example: Easy Read, large font, and pictures, if that would be helpful for you.

➤ **Benefits**

We want to provide a platform for people with learning disabilities to express their views and opinions about hearing services. We will use these insights to make recommendations to Hearing Service providers for how they can improve their services. We hope that participants will find this a beneficial experience.

➤ **Will I be compensated for taking part?**

As a thank you for taking part, you will receive a £10 'Love2shop' voucher (<https://www.highstreetvouchers.com/gift/love2shop>). This will be given to you at the end of the focus group.

➤ **What happens if I do not want to take part, or I change my mind?**

It is up to you to decide whether or not to take part. You should read this information sheet and then decide if you want to take part. If you want to take part, you can contact a member of the research team using the details on the final page of this document. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form or to indicate witnessed verbal consent. If you decide to take part, you are still free to withdraw at any time without giving a reason and without any negative consequences to you. If you do not want to take part, you do not need to contact us.

We will audio-record (voice only) the focus groups so that we have an accurate record of what you say. Participants should be comfortable with being audio-recorded. It will not be possible to decline being audio-recorded but you will be able to leave the focus group at any time. If you do leave, it will not be possible to remove what you have said up to that point, as it is part of a group conversation.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to take part in this research study, we will need to collect information that could identify you. This is called 'personal identifiable information'. We will need to collect:

- Your name.
- Your email address and telephone number.
- An audio recording of the focus group.

We will store all this personal information securely and we will not share personal information with anyone except the team at The University of

Manchester. Audio-recordings will consist of a full audio recording of the focus group. The researcher will say when the recording begins and ends.

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings. This would be in the form of a transcript of the focus group you took part in, once all identifying information has been removed.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please see our [Privacy Notice for Research](https://documents.manchester.ac.uk/display.aspx?DocID=37095) (available at: <https://documents.manchester.ac.uk/display.aspx?DocID=37095>)

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential, and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Only the study team at The University of Manchester will have access to your personal information, and they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with an identifier which will be anonymous.

Improving Hearing Services for People with Learning Disabilities

Only the study team will have access to the key that links this identifier to your personal information. Your consent form will be retained for 5 years after the completion of the project. Forms will be stored in a locked cabinet on the premises of the University of Manchester.

- Identifiable information, such as names of people and services, will be anonymised at the point of transcription. This will ensure that it is not possible to identify you in the reported outcomes of the study.
- Your participation in the focus group will be audio-recorded using a password-protected University of Manchester laptop or iPad. The recordings will be removed from this device and stored on the University of Manchester's Research Data Storage (RDS) system within a password-protected folder, which can only be accessed by the research team. This will be completed as soon as possible following the completion of the focus group. The recording device will not be left unattended, or will be locked away, until the recordings have been removed from the device.
- The audio-recordings will be written up digitally (transcribed) for the purposes of analysis. Transcription will be completed automatically, using NVivo (data analysis software). These transcripts will be checked against the audio-recordings by a member of the research team as soon as possible after the focus group. This will be done in a private environment using headphones so only the transcriber will be able to hear the focus group conversation. Personal identifying information will be removed in the final transcript. Transcripts will be stored on the University of Manchester's Research Data Storage (RDS) system within a password-protected folder, which can only be accessed by the research team.
- If you decide to take part and would like a summary of the research findings to be emailed to you, you can consent to your email being stored for this purpose. Email addresses will be stored securely on the University of Manchester Research Drive in a password-protected folder, separate from the main study data. Otherwise, participant email addresses will be deleted once the focus groups are finished. There will be no more contact after this point.

➤ **Potential disclosures:**

Improving Hearing Services for People with Learning Disabilities

- If, during the study, we have concerns about your safety or the safety of others, we will inform an appropriate person or organisation (e.g., member of your care team/family member/safeguarding through local learning disability nursing team/police, as appropriate).
- Individuals from the University of Manchester or other regulatory authorities may need to review the study information for auditing and monitoring purposes, or in the event of an incident. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

If you wish to complain or have any concerns about any aspects of this study or the way you have been approached or treated during the course of this research, please contact Siobhan Brennan (Project Lead) using the contact details below.

➤ **Contact details for complaints:**

Siobhan Brennan

Tel: 07917605544

Email: Siobhan.Brennan@manchester.ac.uk.

If you wish to make a formal complaint to someone outside of the research team, or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester,

Improving Hearing Services for People with Learning Disabilities

Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information \(available at: https://ico.org.uk/make-a-complaint/\)](https://ico.org.uk/make-a-complaint/).

Telephone: 0303 123 1113.

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s):

Siobhan Brennan

Email: Siobhan.Brennan@manchester.ac.uk

Telephone: 07917605544

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

Division of Human Communication, Development and Hearing

Marianne Day

Email: Marianne.Day@manchester.ac.uk

Division of Human Communication, Development and Hearing

Additional information in relation to COVID-19

Due to the current COVID-19 pandemic, we have made some adjustments to the way in which this research study will be conducted that ensures we are adhering to the latest government advice in relation to social distancing as well as taking all reasonable precautions in terms of limiting the spread of the virus. You should carefully consider all of the information provided below before deciding if you still want to take part in this research study. If you have any additional queries about any of the information provided, please speak with a member of the research team.

Are there any additional considerations that I need to know about before deciding whether I should take part?

We will be holding face-to-face focus groups once the UK Government's Coronavirus restrictions allow groups to meet indoors (at the moment this is projected to be from the end of June 2021). There may still be some additional risks of infection caused by travelling to and from the venue and coming into contact with other research participants and the research team. People with Coronavirus symptoms should not attend the focus groups. We will contact you before the meeting to ensure that you, and anyone who will come with you, are not showing symptoms.

What additional steps will you take to keep me safe while I take part?

Participants will be seated at least 1m apart. Seating and tables will be disinfected before and after the groups. Masks should be worn when arriving and departing (unless you are exempt, or this is no longer required according to Governmental regulations). Materials will be provided to each participant to remove the need to share materials (e.g., single use pens and papers). If resources are to be shared they will be cleaned before passing to another participant. The researchers will do a lateral flow in the 24 hours before the focus groups. We will only attend if the results are negative. We are not asking participants to take a test.

What if the Government Guidance changes?

If Government Guidance changes it may be necessary to cancel the focus groups. If this happens we will arrange online groups instead. In this case you will be provided with further details which you will be able to consider

Improving Hearing Services for People with Learning Disabilities

before agreeing to participate. We will still take the precautions listed above even if Government Guidance removes all social distancing restrictions.

What if I have additional queries?

If you have any questions about these additional guidelines please contact the researcher(s):

Siobhan Brennan: Siobhan.Brennan@manchester.ac.uk.

Telephone: 07917605544

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

Division of Human Communication, Development and Hearing

Marianne Day: Marianne.Day@manchester.ac.uk.

Division of Human Communication, Development and Hearing