Improving hearing services for autistic people (ALDAP)

Participant Information Sheet

You are being invited to take part in a research study which aims to understand the challenges and barriers that autistic people face when they access Audiology (hearing) services 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.

Please visit the study website for videos about the study:
https://sites.manchester.ac.uk/aldap/

About the research

➢ Who will conduct the research?

This project is being led by Dr. Siobhan Brennan at the University of Manchester. Siobhan is an Audiologist. Focus groups will be run by at least two of the researchers: Siobhan Brennan, Shanice Thomas, Marianne Day. All members 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 Region).

➢ What is the purpose of the research?

The NHS have recognised that healthcare, including Audiology (hearing) services, need to be improved for autistic people and people with learning disabilities. Autistic people and people with learning disabilities are more likely to have undiagnosed and unaddressed hearing loss. If hearing loss is not identified or addressed, this can impact on a person’s quality of life, behaviour, and ability to communicate. This study aims to identify the challenges and barriers autistic people face when they access hearing services or try to access hearing services. The findings will be used to provide guidance and recommendations for hearing services about how to improve their services.

You have been approached to take part in this study because you are autistic, or you are a parent/guardian or carer of an autistic person, and you live in the United Kingdom (UK). We want to include autistic people who have used hearing services, and those who wanted to use these services but were unable to. We want to recruit around 18 autistic adults to take part in three different focus groups. We would like to hold focus groups with parents/guardians or carers.

➢ Will the outcomes of the research be published?

We will share what we find out about the challenges of accessing Audiology (hearing) services with Health Education England, professional Audiology providers, and autistic people and their caregivers. 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 (can be found at: https://sites.manchester.ac.uk/aldap/) and on social media. 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 (2021-11714-19995).

➢ Who is funding the research project?

This project is being funded by Health Education England.

What would my involvement be?

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

If you give your consent to take part in this study, you will be asked to take part in one focus group. Each focus group will include between 4-6 adults. Due to the Covid-19 pandemic, focus groups will take place online using Zoom videoconferencing. To take part, you will require access to a computer or other electronic device compatible with Zoom (such as a mobile phone or tablet/iPad), which is connected to the internet.

If you need help to set up or use Zoom, please visit this website or ask the researchers: https://www.autistica.org.uk/get-involved/get-involved-1-1/guide-to-webinars-on-zoom.

The researchers will have their cameras turned on in the focus group so you will be able to see us. We would like to see you too. We ask that you have your camera turned on. If you are not comfortable with this, you can have your camera off. The researchers will be based in their home or workplace to hold the focus groups. They will ensure that nobody else is able to hear the conversation. The focus group will take place on a date and time that is convenient for you.

Focus groups will be led at least two members of the research team (Siobhan Brennan, Shanice Thomas, Marianne Day). Focus groups will take up to 1 hour and will be audio-recorded (voice only) using Zoom videoconferencing. We will not record the video. You will also be able to type your views in written messages, in the Zoom chat. The chat messages will be saved.

During the focus group, we will ask questions about your experience of accessing Audiology (hearing) services, either for yourself, or on behalf of an autistic person. 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 (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?

You do not need to tell us anything you do not want to. You do not have to explain the diagnoses or care you have had. We will only ask about your experiences of accessing hearing services. We encourage participants not to name specific audiologists or clinics, where possible. Instead, we ask that you describe the type of service you accessed.

We will show you some resources and information that hearing services use to communicate with autistic people. For example, leaflets, emails, and forms. We would like to know what you think of these resources and whether you think they could be better.

➢ Risks

It is unlikely that you will become upset or distressed during the focus group. However, it is possible that this could happen. To reduce the risk of this happening, we will make our focus groups comfortable for you. We will pause or discontinue the focus group if required. You are free to leave at any time if you want to, without giving a reason.

➢ Making focus groups comfortable for you

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 researchers will arrange to speak with you 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 ways, for example: using text in bullet points, large font, and pictures (as appropriate).

➢ Benefits

We want to provide a platform for autistic people to express their views and opinions about hearing services. We will use these insights to make recommendations to Audiology staff 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 sent to your email address after the focus group has taken place.

➢ 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.

As we would like to audio-record the focus groups, participants should be comfortable with being audio-recorded. It will not be possible to decline being audio-recorded. However, you will be able to pause the recording and you will be free to leave at any time. You should be comfortable with the chat messages being recorded.

It will not be possible to remove your data from the project once it forms part of the data set, as we will not be able to identify your specific data. This does not affect your data protection rights.

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 and a recording of the chat messages.

We will store all this personal information securely and we will not share it with anyone except the research team at The University of Manchester. Audio-recordings will consist of a full audio- recording of the interview. 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. 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.

➢ 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, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random name (called a ‘pseudonym’). Your consent form will be retained for 5 years after the completion of the project. These will be stored on the University of Manchester secure Research Data Storage (RDS) system, according to the University’s Retention Schedule.

- Identifiable information, such as names of people and services, will be anonymised using replacements in transcripts, to make sure that it is not possible to identify you in the reported outcomes of the study.

- Your participation in this research will be audio-recorded Zoom and your personal data will be processed by Zoom. The chat messages will also be recoded in Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on the University of Manchester secure Research Data Storage (RDS) system for 5 years, according to the University’s Retention Schedule. This will be completed as soon as possible after the focus group has taken place. Click here for the Zoom privacy notice.

- The audio-recordings will be written up digitally (transcribed) for the purpose of analysis. Transcription will be completed using NVivo software. Audio-recordings will be listened to and transcripts will be produced in a private environment using headphones, so nobody else is able to hear the conversation. Transcripts will be created within 24 hours after the focus group and will only be stored in university approved secure locations. Any personal identifying information will be removed in the final transcript.

- If you decide to take part and would like to receive 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 Data Storage system. Otherwise, participant email addresses will be deleted once the focus groups are finished. There will be no more contact after this point.

➢ Potential disclosures:

- If, during the study, we have concerns about your safety or the safety of others, we will inform your GP/care team/family member.

- Individuals from the University, the site where the research is taking place and 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 Brennen (Project Lead) using the contact details below.

➢ Contact details for complaints

If you have a complaint that you wish to direct to members of the research team, please contact:

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, 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 Tel 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

SHANICE THOMAS

Email: SHANICE.THOMAS@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?

The focus groups will take place online, so you can attend from your own home. We understand that some people may want to attend a focus group from a place or organisation outside of their own home, such as at a local support group. If you intend to do this, it will only be possible when Government Guidance permits, and if the organisation permits. If you intend to do this, you must follow these rules:

- You should not leave your home if you have Coronavirus symptoms.
- You must follow social distancing and other rules at the place/organisation you attend.

What if the Government Guidance changes?

If Government Guidance changes, the study will still take place online.

What if I have additional queries?

If you have any queries about these additional guidelines, please contact the researchers:

SIOBHAN BRENNAN

Email: SIOBHAN.BRENNAN@MANCHESTER.AC.UK

Telephone: 07917605544

SHANICE THOMAS

Email: SHANICE.THOMAS@MANCHESTER.AC.UK