

Improving hearing services for autistic people (ALDAP)

Information Sheet – Children and Young People

You can find videos about the study on our website:

<https://sites.manchester.ac.uk/aldap/>

About the research

➤ **Who is carrying out the research?**

My name is Siobhan. I work with Shanice and Marianne. We work at the University of Manchester.

We would like to invite you to take part in our research study about how we can make hearing services better for autistic children and young people.

Before you decide if you wish to take part, please make sure that you understand:

1. Why the research is being done.
2. What your involvement in the study will be.

Take your time to read through this information sheet before you decide if you wish to take part. Ask as many questions as you wish.

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

The purpose of the research is to find out what challenges autistic people face when they use Audiology (hearing) services or try to use these services. We want to make hearing services better.

- Every day we use our ears to hear sounds and noises.
- Sometimes people find it hard to hear.
- If you find it hard to hear, you can go to a place called 'Audiology'. This is where you will see an audiologist.
- The audiologist can check your ears and test your hearing. They can help you to hear better.
- You might have had a hearing test before. Or your parent/guardian wanted you to.
- If you did not see an audiologist in the end, we want to know why it did not happen.
- Siobhan is an audiologist.

➤ **What do you want to ask me about?**

- We want to ask you about what it is like to see an audiologist or have a hearing test.
- We want to know what was good and what was bad.
- We want to ask you how to make Audiology (hearing) services better.

- We would also like to show you some information that audiologists use, such as leaflets and forms.
- We want to know what you think about this information and if it could be better.

➤ **Why are we doing this research?**

The aim of this research study is to find out what challenges autistic people face when they use hearing services. We want to find out how hearing services can be made better.

We will use what we find in this study to provide guidance and advice to staff in hearing services about how they can improve their services.

➤ **Why have I been asked to take part?**

We have asked you to take part because:

- You have autism.
- You have used hearing services, or you tried to use hearing services.
- You are aged 10 years or above.
- You live in the United Kingdom (UK).

➤ **What would I be asked to do if I take part?**

We would like to ask you these questions ask in a group meeting, called a focus group.

- The focus group will involve speaking in a small group with us (Siobhan, Shanice, Marianne), other autistic children/young people, and parents/guardians.
- We would like you to take part in 1 focus group.
- There will be up to 6 autistic children/young people at the focus group. Parents/guardians will be at the group too.
- You do not have to tell us anything you do not want to.
- You do not need to explain any hearing problems or care you had from hearing services if you do not want to. We will only ask what you think about hearing services.

➤ **How long is the study?**

The focus group will take up to 1 hour, or it might be less.

➤ **Where will the study take place?**

The focus group will take place online, using Zoom. You can attend the focus group from a computer, mobile phone, or tablet/iPad, which is connected to the internet.

You will be able to see us (Siobhan, Shanice, Marianne).

We would like to see you too. We ask that you have your camera turned on. But you do not have to.

We would like to record what you say in the focus group. We will only record the conversation, not the video. You will be able to type what you think about hearing services at the focus group, in the Zoom chat. We will save the chat comments.

➤ **Will my participation in the study be confidential?**

To take part in the research, we will need to collect the following information about you:

- Your name.
- Your parent/guardian's contact details (email address and telephone number).
- A recording of what you say in the focus group, and a recording of the chat comments.

Only the research team at The University of Manchester will have access to your information and we will ensure it is kept safe and secure.

We are keeping this information safe and following data protection law.

The University of Manchester is the Data Controller, which means that we will protect the information about you. All researchers have received training to do this and we will make sure that they keep your information safe.

We will make sure that no one knows you have chosen to take part in the study and will also not share any information you have given to us. To do this we will use a process called anonymising, which means that we will generate a secret code for you and make sure that your name is stored in a different place to the rest of the information you give us.

We will also keep the information you give us for 5 years in accordance with the University of Manchester retention schedule and then it will be safely destroyed.

You have a number of rights under data protection law, including the right to see any of the information you have shared with us. If you would like to know more about your rights or find out the legal reason we collect and use your information, please read through the [Privacy Notice for Research](#) or discuss it with your parent/guardian.

We will write reports about what we found in this study. We will not include your name or any other information that could identify you in our reports.

➤ **Do I have to take part?**

No, you do not have to take part. It is completely up to you if you wish to take part in the study. Make sure you think carefully and consider all the information contained in this sheet before you decide.

After you have decided you will be asked to sign an assent form that shows you understand what will happen and agree to take part in the research. Your parent/guardian will do the same (sign a consent form) if they agree for you to take part.

➤ **What if I change my mind?**

You are free to leave or withdraw from the study at any point without having to give a reason. It will not be possible to remove what you say in the focus group when we combine what everyone said. Please remember that your data will be made anonymous and you will not be identified in any way.

➤ **Who is organising and approving the research?**

The research is being sponsored by the University of Manchester. It is being funded by Health Education England.

The research has been approved by the University of Manchester Research Ethics Committee, a group of people who work to protect your safety, rights, wellbeing, and dignity.

➤ **What do I do now?**

If you have any questions about the information in this sheet, please let us know:

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If you want to know more about this study, you can visit our website at: <https://sites.manchester.ac.uk/aldap/>.

Thank you for reading this.