Participant Information Sheet

For Parent(s)/Carer(s)

A research study adapting autism assessments for deaf children and young people

You can access the BSL version on our research website www.comic.org.uk

Please talk about this research with your family/friends. Please contact us if you have any questions about this study. Our contact details are at the back of this leaflet.
About our study
At the moment there are no autism spectrum disorder (ASD) assessments for deaf children. ASD assessments are for hearing children. This project wants to change the assessments so they work with deaf children.

We will look at three different assessments:
• Social Responsiveness Scale (SRS-2): this is a questionnaire that parents fill in.
• Autism Diagnostic Observation Schedule (ADOS-2): this is a play based session with the child.
• Autism Diagnostic Interview - Revised (ADI-R): this is an interview with parents.

These assessments can help doctors or psychologists see if hearing children have ASD. This means they can give the right support to children and their families.

The research team set up a group of people from around the world who work with deaf children with ASD. They have looked at the three assessments. They gave us ideas of how to change the assessments.

We changed the assessments so that they can be used with deaf children who may have ASD.

We hope these assessments will help deaf children with ASD, and to help give their families the right support.

Why have we asked you to take part in this project?
You are a parent/carer of:
• a deaf child
• a deaf child with ASD
• a hearing child with ASD
Your child is 2 to 18 years old.

We would like you to help us, to see if the new assessments can see the differences between deaf children without ASD and deaf children with ASD.

Before you decide
A person from our research team can meet with you and your child.

We can meet you:
• At your home
• Via FaceTime
• Via phone call

The visit will last about 1 hour.

What we will talk about:
• We will talk about this project. This gives you the chance to ask any questions.
• We will give you a form called the “Consent Form”. This is a form that you sign to say that you agree to be involved in the project. We have the “Consent Form” in BSL; please ask if you would like us to send it to you.
• We will give you time to think about it. If you sign the “Consent Form”, then you can be involved in this research.
• We will give you a form called a “Demographic Questionnaire”. The form has questions about your child and your family. This can be filled in after you have signed the “Consent Form”.

After consent has been given
• SRS-2 - This is a self-reporting parent questionnaire which is available in English and BSL. You will need to complete this twice.
• SCQ - This is another self-reporting parent questionnaire. It is completed on a computer and you will only need to do this once. This can be completed at any point during your participation in the research.
Clinical Interview:
Who will be involved?: One of you (parents/carers) and your child will meet with a clinician.
Where?: At your home or a different place if you prefer.
What will you do?:
• Answer the clinician’s questions in the Clinical Interview.
If we need extra information after all the above then we might ask for your permission:
• For additional reports
• To contact your child’s school
• To observe you playing with your child at home
We will not do any of these extra things without your permission.
If your child has a diagnosis of ASD: The clinician will access your child’s medical records and look at the time when the diagnosis of ASD was given. This is to see if any extra assessments were carried out at that time which can explain why they have made the ASD diagnosis.
This is not a diagnosis for your child. This will not affect the support you receive now.
How long will this last?: About 1 hour.

ADOS-2:
Who will be involved?: One of you (parents/carers) and your child will meet with a clinician, a researcher and a British Sign Language interpreter if needed.
Where?: A venue suitable for the ADOS-2 session. We will aim for this to be near your home.
What will you do?:
• Your child will do the play session (ADOS-2) with a clinician and a second clinician will observe this play session.
You (parent/carer) are welcome to be in the room with your child.
We will have a video camera which will record the play session.
Why is your child doing the ADOS-2?: The ADOS-2 has been changed and we want to see if it is better for deaf children.
Why are we videoing the ADOS-2?: Two different clinicians will watch the video recording to see if they agree with what the clinicians saw during the play session.
How long will this last?: About 1 hour.

ADI-R:
Who will be involved?
One of you (parents/carers) and your child will meet with a clinician. We will book a British Sign Language interpreter if needed.
Where?
At your home or a different place if you prefer.

What will you do?
You (parent/carer) will do the ADI-R interview with a clinician.
How long will it last?
About 2 hours.

Optional feedback: We have a feedback sheet which will ask you about your experiences and anything that you feel needs to be improved. It is your choice if you want to fill in this feedback.

How will we use the information from the assessments?
The information from the clinical interview and SCQ will decide which group your child will be in:
• Deaf with ASD
• Deaf without ASD
• Hearing with ASD
The ADOS-2, ADI-R and SRS-2 assessments are the research tools that we are testing.
What will we do with the video and the information after we have met you?
The video clips will be passed to the other two clinicians in a secure way. They will watch the videos on a secure network.
We will only keep the video clips until the project is finished and then we will delete the video clips.

Optional - Future Training
Once this research project has finished we would like your permission to keep a copy of the ADOS-2 video recording, for future research and training. Before your video recording is used the research team will contact you to give you information about the new project and to check if you are still happy for us to use it. This is optional and your decision will not affect whether you can participate in this project or any support you may currently be receiving.

What are the risks?
There are no risks to taking part in this research. We are testing whether the changes that we have made to the assessments work well for deaf children. This research will not change any support that you and your family might be receiving.

The research assessments will not change a diagnosis that your child has already been given. If you have any concerns during this research, or would like some additional support, the research team can help you to contact your local services to discuss this.

What are the pros (+) and cons (-) of being involved?
You being involved in this research is a way of helping to make healthcare services more accessible to deaf children. This means if your child or other children need these services in the future, hopefully healthcare services will be able to provide more appropriate help.

We understand that this research will take time if you decide to take part. Unfortunately we are not able to make the assessments any shorter.

The research team will offer your family a voucher as a way of saying thank you for giving up your time to be involved.

What are the benefits of being involved?
You being involved in this research is a way of helping to make healthcare services more accessible to deaf children. This means if your child or other children need these services in the future, hopefully healthcare services will be able to provide more appropriate help.

Will I find out the results of the research assessment?
This research tests whether the assessments work well with deaf children. The research assessment will not change a diagnosis which has been made before the research started. If you would like information about your child’s assessment then you can ask for this. The research team will ask the clinician to give you information about where the assessments have identified specific strengths that your child has, and any areas in which the assessments have suggested your child might benefit from support. If you would like some more support, after your family have completed the assessments, the research team can help you to contact your local services to discuss this.

Does my child have to take part?
No, you and your child do not have to take part in this research. If you decide to take part and then change your mind, you and your child are able to withdraw at any time; you do not need to explain why you have decided to withdraw. If this happens then we will keep the information you have given us. If you are not happy with this, then you can ask us not to keep any of your information.

Are my travel costs covered?
The research team will pay your travel costs and will give your family a £40 voucher to thank you for participating in the research.
Who has reviewed the study?
All research in the NHS is looked at by the Research Ethics Committee, to protect your interests. This study has been reviewed and approved by Yorkshire & The Humber – South Yorkshire Research Ethics Committee.

Who is funding this research?
This research is supported by the Medical Research Council (MRC) through the Biomedical Catalyst: Developmental Pathway Funding Scheme. This study is running for 3½ years.

Information about PALS
If you would like to give a compliment or make a complaint, please contact our Patient Advice and Liaison Service (PALS) using the following details:

Freephone: 0800 052 5790
E-mail: pals.lypft@nhs.net
Write to:
The PALS Office,
Becklin Centre, Alma Street,
Leeds, LS9 7BE
Visit: www.leedsandyorkpft.nhs.uk/service_users/PALS

Please contact us if you want to know about the study.

Helen Phillips:
Email: researchdiads.lypft@nhs.net
Phone: 01904 294827
Text message: 07973 630601
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Professor Barry Wright:
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If you decide to take part in this research...
We would love to hear about your experiences of being involved and the assessments that you are part of.

Thank you for taking time to read this leaflet.