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Understanding the changing needs of autistic children in speech and language therapy services: exploring child's priorities and preferences alongside current practice.

Phase Two: Speech & Language Therapists Information Sheet (PIS)

You are being invited to take part in a research study, which aims to explore Speech and Language Therapy practice for autistic children. We are interested in how you, as a specialist clinician, currently provides support, what you see as the new and emerging concerns for the profession and what working solutions you are employing to meet these needs. In particular, we want to know more about meeting the needs of under-resourced groups, like autistic girls and children with higher verbal ability, as well as how you respond to community calls for more autism affirming practices.

Before you decide whether to take part, it is important for you to understand why the research is being conducted 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 by contacting the researchers directly: [email placeholder] .

Thank you for taking the time to read this information sheet.

The research study

Who will conduct the research?

Based at The University of Manchester (UoM)
Dr Alexandra Sturrock (Chief Investigator), Autism researcher & Speech & Language Therapist
Dr Katherine Twomey (Co-Investigator), Researcher in Language Development
Dr Kathy Leadbitter (Co-Investigator), Highly Experienced Autism Researcher
Sarah Thorp, Research assistant

Based at The Manchester University NHS Foundation Trust (MFT),
Alison Hunter (Principal Investigator), Highly Specialist Speech & Language Therapist

Based at The University of Sheffield (UoS).
Carla Rohde (Co-Investigator), Highly Specialist Speech & Language Therapist

This study is being sponsored by Manchester University NHS Foundation Trust (MFT) and funded by the National institute for Health and Care Research (NIHR).

What is the purpose of the research?

Our understanding of autism is evolving, meaning healthcare providers, such as Speech and Language Therapists (S&LTs), need to respond by adapting clinical services. Recent changes to diagnostic criteria have increased numbers of autistic children without language or cognitive disability accessing services. While better recognition of previously under-represented groups (such as women and girls) means therapies need to address an increasingly diverse set of needs. Additionally, S&LTs has been criticised by autistic adults, for relying on methods that focus on correcting 'deficits' in autistic children, rather than taking a stance that embraces someone's autistic identity. Deficit-focussed practices, they suggest, may undermine the individual's confidence, access to community and contribute to mental ill-health. However, with alternative practices poorly understood, many S&LTs are experiencing a crisis in how to provide best therapy practice.

As part of a larger study, we will explore the views of children and SLTs, outlining areas of good practice, identify gaps in current provision and highlighting difficulties meeting clinical needs. Results will provide guidance for clinicians deciding how to offer services to this group and researchers developing new interventions.

In this phase of our research, we undertake essential consultation with S&LTs, key stakeholders in the field.

We will recruit 40 S&LTs to take part in a 30-minute online survey, where we will ask about current practice and how you and those around you are meeting changing demands from service users.

If you would also like to take part in a follow-up, 60-minute, interview, you can also opt to do this within the survey. In the online interview we will discuss what you see as the barriers to best practice for autistic children, your solutions to these issues and what we need in place to ensure best practice in the future. We will select 12 S&LTs to take part in this additional interview, selecting a range of people to give a diverse set of views.

Why have I been asked to take part?

We are looking for people who are (1) qualified as a Speech and Language Therapist; (2) who works or who have worked in autistic children's service provision, (3) are based in the UK.

Clinicians with various neurotypes will be beneficial to our study findings and there are no exclusionary criteria regarding any existing diagnoses.

What will happen with the results of the study?

The aim is that findings from this study will contribute to choosing particular clinical approaches, informing commissioning decisions and guiding clinical research. This is part of a wider body of work. We will publish findings in academic journals targeting Speech and Language Therapy, researchers and clinicians.

We will offer a summary of all results to participants, which you can access either through our social media updates, or by joining our mailing list (you can indicate you would like to receive email updates on the consent form). We will also share findings with governing bodies and the autistic community.

Please be aware that any published materials would use pseudonyms, not real names. You would not be identifiable to anyone outside of the research team.

Who has reviewed this research study?

All research in the NHS is approved by the Health Research Authority (HRA) and reviewed by an independent group of people called a Research Ethics Committee (REC). The Research Ethics Committee is made up of experts, non-experts and members of the general public. Together they review research applications to ensure your safety, rights, wellbeing and dignity are protected at all times.

This study has been reviewed and given favourable opinion by XXXX.

Participant involvement

What happens if I agree to take part?

You have received this information sheet because either you saw our advert and contacted the research team at UoM yourself, or you were directly approached by the Principal Investigator from MFT Speech and Language Therapy services. This means you are already in touch with our research team, either by email or via the Principal Investigator.

Next steps

Please **read this information sheet fully** and ask a member of the research team any questions you may have. We can arrange a meeting or you can ask questions by email.

If you were recruited by the Principal Investigator at MFT the process looks like this:

1. If you would like to take part in the study, **please return the completed the consent form** to your research team contact.
    - You can find the consent form in the same email or letter that came with this information sheet. Or you can go to the link at the end of this document to fill in the online consent form.
    - If you fill in the online consent form, there is nothing else you need to do, the information will come directly to us.
    - If you fill in a paper copy of the consent form you can either scan and send it back to us by email or return it by postal mail or hand it in in-person to your contact at MFT.
2. Your contact details will then be **passed on to the research team** at UoM, who are conducting the surveys and interviews for this study.

If you contacted the UoM team after seeing our advert online the process looks like this:

1. If you would like to take part in the study, **please return the completed consent form to your research team contact**.
    - You can find the consent form in the same email that came with this information sheet. Or you can go to the link at the end of this document to fill in the online consent form.

- You should fill in the online consent form, there is nothing else you need to do, the information will come directly to us.

2. Once we have received confirmation of consent, we will arrange a video call meeting to do an eligibility check. We will ask you to confirm your qualification as an S&LT. You can do this by showing us your documentation, or providing us with your **RCSLT registration number**, we do not need to retain a copy.

The survey

1. Once eligibility and consent are confirmed, researchers at The University of Manchester will send you a **link to complete the online survey**. It should take **30 minutes to complete**.
2. Questions will cover:
   - Demographic information such as locality and type of service, years of working as an S&LT and an overview of your typical client group.
   - What supports are currently being offered to autistic children in your service
   - How you are currently meeting the needs of newly emerging populations, such as girls and those with good language/learning ability
   - How you are currently integrating autism-affirming principles into your practice
3. At the end of the survey, **you will have the option to take part in a follow-up, 60-minute, interview**.

The optional Interview

1. If you opt to take part in an interview, a member of our team will be in touch by email to arrange a time and date for this.
2. We will only interview 12 S&LTs and we need a broad representation of views and clinical backgrounds, so if you opt to take part you *may* not be selected to have an interview. We will let you know by email, either way.
3. The interview will be conducted on a **one-to-one, video-call,** with a researcher. It will be **audio recorded**.
4. Questions will explore:
   - Your concerns regarding offering appropriate support to emerging populations
   - What you would consider to be the barriers to autism-affirming practices
   - How clinicians are changing practices to meet new demands
   - What you would consider to be good practice in these areas
   - What changes are needed to ensure best practices in the future

5. If you want to (or need to) you can put some of your responses in the Zoom chat space during the meeting.
6. After you have finished the survey and/or interview you will be thanked for your contribution. We will re-confirm your preference to stay in touch with the project through our website and social media sites or emails. We will arrange your participant voucher payment.

Will I be compensated for taking part?

There is a £10 voucher available for all participants in our survey. There is a further £20 voucher available for all participants in the interview.

What are the possible benefits of taking part?

We cannot guarantee any specific benefits from taking part in this research. However, research does deliver wider benefits to society or others with a similar condition. Our ambition is that this research will provide greater guidance for S&LT offering services to autistic children.

What are the possible disadvantages and risks of taking part?

1. There is a time commitment when taking part in this study. We are offering a one-off payment in line with your participatory activities. If you would like to stay informed about the study, we will also provide summary updates on our results. This can be accessed via our social media site, or via email (if you choose to be added to the mailing list).

2. Audio recordings are required for the interview to ensure we capture all your views accurately. Participants should be comfortable with the recording process at all times, and it will be possible to stop recording for periods to facilitate this. Using Zoom video call recordings will mean that we can isolate the audio recording and only save this for our research. All recordings will be deleted from the zoom history as soon as the audio data is saved on our secure servers.

3. We do not anticipate any distress will be caused by being involved in this study. However, should you experience any distress, you are welcome to tell the researcher during the interview or contact our research team: [placeholder email here]

Do I have to take part?

No, you do not have to take part if you do not wish to.

What happens if I change my mind?

Taking part in this study is completely voluntary and if you decide at any point, you no longer want to take part you can withdraw from the study. However, it will not be possible to remove your data from the project once it has been anonymised or analysed, i.e., integrated into a dataset, as we will not be able to identify your specific data. This does not affect your data protection rights. You are welcome at any point to let us know of your decision to leave the study by emailing: email placeholder

What happens if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak with the lead researchers who will do their best to answer your questions

[Insert PI/ Study team contact Details]

If you remain unhappy and wish to complain formally, you can do this by contacting local NHS Patient and Liaison Service (PALS) or equivalent: pals@mft.nhs.uk

Manchester University NHS Foundation Trust is insured to carry out clinical research through the NHS Indemnity scheme, however the normal National Health Service complaints procedures should be available to you. In the event that something does go wrong and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against Manchester University NHS Foundation Trust, but you may have to pay your legal costs.

How will we use information about you?

We will need to use information from you for this research project. This information will include the following:

- Confirmation of professional qualification
- Years working as an S&LT
- Years working with autistic children
- Your locality (Northwest UK, Southeast UK, etc…)
- Your service type (CAMHS, community clinic, schools, etc.)
- Demographics of children accessing service (age, educational/language levels, etc.)

Also:

- Your sex/gender
- Your age
- Your ethnicity
- Your neurotype

We are collecting some of this data to ensure there is a diverse representation within our sample, and to check your eligibility to take part. Many of the items are essential for taking part in the study. However, you do not have to disclose your ethnicity, sex/gender identity or neurotype if you do not want to.

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure by:

- Storing data on a password protected secure server at The University of Manchester and the Manchester University NHS Foundation Trust.
- Removing your name and any other identifying information from data before analysis. This will then be allocated a Participant ID number.
- Retaining a key that links your ID number to your personal information securely and separately from other data files.
- Encrypting files containing personal information and storing them on a secure server separately from the study data.
- Storing all paper documents securely at the respective research site, i.e., at The University of Manchester or Manchester University NHS Foundation Trust.
- Processing audio recordings in a secure way, i.e., removing this audio data from the Zoom platform and transferring it to a secure server via an encrypted laptop provided by The

University of Manchester, then transcribing recordings into a written document, ready for analysis.
- Only allowing personal information and identifying data to be accessed by the required members of the research team.

Qualtrics will be used to collect some of the study data and to record consent. This is a secure web application for building and managing online surveys and databases. It is recommended as a secure platform for collecting survey data by UoM. Data you input is not owned by Qualtrics. It is GDPR compliant. Once data is collected UoM, will download data and store securely on their own secure server.

Your data will not be shared outside the UK

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 5 years. The study data will then be fully anonymized and securely archived.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- If you agree to take part in this study, you will also have the option to take part in future research using your data saved from this study. This would mean us placing your anonymised survey (and/or interview) data in a secure research data repository, such as https://osf.io/.

Where can you find out more about how your information is used?

- You can find out more about how we use your information
- at www.hra.nhs.uk/patientdataandresearch
- at https://research.cmft.nhs.uk/getting-involved/gdpr-and-research
- by asking one of the research team
- by sending an email to [placeholder email]

Contact Details and Next Steps

If you have any queries about the study, then please contact the researchers directly: [Email to team]

Once you have read the information sheets and asked any questions you might have, if you would like to take part in the study, please complete a consent form via one of the following methods: Online via [Qualtrics link]

If you were given this information sheet by the Principal Investigator at MFT you can also return the completed consent form via the following additional methods:

1. Bringing the completed consent form to the PI at MFT at work
2. Scanning the completed consent form and emailing it to [Email address]
3. If you were contacted by postal mail, you can also post your consent form to us using the enclosed stamped address envelope.

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Thank you very much for your time in considering this request and please do not hesitate to contact us should you require any further information or if you would like to discuss your participation in the study further.

Please keep a copy of this INFORMATION SHEET for your reference.