

Slide 1:

We're here today to talk about the work of The SPACE Project, which aims to investigate Speech Perception by Autistic Adults in Complex Environments. The team members are myself (Hannah Guest), George Bendo, Graham Hanks – all of whom are speaking today – as well as Alex Sturrock, Emma Gowen, and Chris Plack.

Slide 2:

We are indebted to the research network Autism@Manchester, which brings together clinicians, researchers, and the autistic community to understand and shape autism research. They run an Expert-by-Experience advisory group, whose members George and Graham identified speech perception as an autism research priority.

Slide 3:

It was important for us to consider the existing literature. There are longstanding personal reports of speech-perception difficulties amongst autistic people. But when we look at the empirical evidence, the picture is a little unclear: we see inconsistent reports, weak effects. And perhaps this isn't entirely surprising if we critically appraise the methods involved:

- Underpowered studies (often <20 autistic participants)
- Rarely corrected for multiple comparisons
- Hypotheses not sufficiently shaped by autistic experience
- Listening conditions isolated, not integrated
- Data-collection methods not designed and refined to suit the needs of autistic participants

Slide 4:

The aims of our project are to shed light on autism-related differences in speech perception, via...

- A more collaborative approach
- Detailed attention to autistic experience
- Listening tasks and research hypotheses based on autistic insight
- Criticism from autistic people on every aspect of our research methods
- Adequately powered research

And the team we've put together consists of two auditory researchers (HG & CP), two autism researchers (AS & EG), and two autistic researchers (GB & GH)

Slide 5:

The project consists of a self-report phase, intended primarily to generate hypotheses, and a laboratory phase, intended primarily to test them. The self-report phase is largely complete and we'll report its results today.

Slide 6:

First up was a small but in-depth study using semi-structured interviews with nine autistic participants without a diagnosis of hearing loss. This work was guided substantially by Dr Alexandra Sturrock. Data underwent thematic analysis, revealing a very rich set of six main themes, 28 subthemes, and 73 tertiary themes.

Slide 7:

This diagram summarises the main themes and subthemes, and their inter-relations.

Slide 8:

The first theme is Auditory Anomalies: aspects of listening that our participants said were substantially different for them than for neurotypicals. For example, difficulties with focusing, orienting, drowning out, and auditory overload.

One participant reported that, *"It's frustratingly hard to focus on somebody when people are talking around me, even if they're being very quiet"*, an idea echoed by most participants. Another said, *"I don't really go to the movie theatre... The bass overtakes the rest of it, and it's just, like, rumbly."*

Another quote was, *"There might be three or four conversations going on. Despite trying to pay attention to one conversation, it's **very** hard to distinguish who's speaking to me. And also, it's not always possible through eye contact to work out where the conversation is coming from."*

And finally, *"I'm not afraid of the crowd, I'm afraid of the **noises** of the crowd"*. The discomfort induced by auditory overload can then feed back into listening difficulties, creating a vicious cycle of discomfort.

Slide 9:

Themes 2 and 3 consider the "Contributing factors" to listening difficulty.

One factor is "Reverberation", for example, *"If I'm in the lecture hall and someone is talking, the echo introduced by the lecture hall itself is enough to make it very difficult for me to understand."* An example I've encountered is when the Sheffield autism service moved to a new location. The interview rooms were so echoey that patients couldn't understand what was being said to them! They had to add soft furnishings and drapes to absorb the unwanted sound.

"Visual cues" were mentioned often: *"If I can't see them start the conversation, I will not pick up that they're talking to me at all."* But other senses can also distract, for example, *"I was trying to listen to the speaker, but someone near me had this really strong perfume or something... it was so distracting."*

Slide 10:

"Compounding factors" are those that don't directly affect listening difficulty, but do affect the **impact** it has on a person's life.

One is "Lack of understanding of by communication partners". For example, *"You're in a crowded environment and you're asking people, '**Can we keep it down a little bit?**' And everyone is going, '**Well it's just as hard for us**'... But I don't think it affects them like it affects me! To them it's probably just an annoyance, whereas to me, it's affecting my entire evening."* I think there's often a problem with non-autistics thinking we exaggerate our experiences, making it difficult for us to obtain reasonable accommodations.

And even professionals can be quite dismissive of autistic hearing problems, perhaps because hearing difficulties are not part of the DSM5 definition of autism. One participant said: *"I often thought, maybe I've just got a problem with my hearing... And then you're told again and again, '**No, no there's nothing wrong**' and you're trying to work out then why can't I hear someone? Why can't I have a normal conversation?"*

Slide 11:

I already mentioned "Impact" of listening difficulties, and these turn out to be really varied and substantial! I'm mentioning a tiny fraction here.

A huge one is "Social participation": *"If I were to go to a party, I can't understand people. So I can't effectively socialise, whether I go or not."*

There's also the "Impression" we make on other people: *"People probably think I don't care very much sometimes, like I'm not paying attention."*

And of course there are "Emotional" impacts, for example, *"It's very stressful because I'm missing stuff, and my head starts going, '**You're not reacting right**' or '**They asked you something and you don't know what they're saying**'."*

The constant stream of embarrassing mistakes and negative reactions from others can be really psychologically harmful, causing many autistic adults to withdraw from society. Of course, autistic people can have social difficulties anyway, but our participants made very clear that listening difficulties are an **additional problem**, that can add to and interact with social difficulties.

Slide 12:

The final theme is "Coping Mechanisms", for example "Communication tactics". As one participant put it, *If I say '**sorry?**' or '**say that again**' and they repeat themselves and I still can't understand them, now I recognise to tell them '**speak louder**', or '**slow down**'."*

Another is “Technology”: *“If we’re out at a restaurant, I’ll wear high fidelity earplugs... So I can hear **him** talk to me, but it lessens the background noise.”*

A further tactic is “Managing the environment”. One student said, *“In classes where we have group discussions, I’ll typically extract my group from the classroom and won’t return.”*

I believe there are great opportunities to develop strategies to help autistic people hear more easily. Some of these could be for individuals, like communication tactics and personal technology. But we also need institutions, venues, and clinicians to meet us half-way by offering better environments, accommodations, and professional guidelines.

Slide 13:

And all these findings are reported in this paper, published in ADLI.

Slide 14:

Our internet survey obtained less in-depth data but from a much larger sample. We analysed data from 79 autistic participants without a diagnosis of hearing loss. The survey consisted of nineteen multiple-choice questions that provided us with simple quantitative data and three open-ended questions that provided us with free-text responses that underwent content analysis, giving data that are largely qualitative but also allow us to count the frequency with which concepts were mentioned.

Slide 15:

We first asked respondents to indicate how easy they would find speech perception in a quiet environment or with either mechanical noise, music, or conversational noise in the background. What is interesting about the responses here is that the respondents indicated that they had as much difficulty when one or two people were talking in the background (as shown in the plot on the upper right) as when loud mechanical noise or music was present (as shown in the bottom centre plots).

Slide 16:

When respondents indicated that they had difficulty with speech comprehension in a specific environment, we also asked if they perceived that they had greater difficulty in these situations than their peers. Note specifically how the respondents perceived having more difficulty with speech perception in environments where other people were talking as shown in the plots on the right.

Slide 17:

Finally, we also asked whether the respondents felt like their speech comprehension issues had impacted their lives, and they generally indicated that this was the case.

Slide 18:

The one takeaway message from this is that autistic people struggle with listening when just one background conversation is taking place and that this is almost equivalent to the difficulty caused by loud background machinery or loud background music.

Slide 19:

The responses to the open-ended questions, two of which are shown here, generally reinforced the findings of the interview study. However, we also identified some new themes in these responses, in part because of the larger sample and in part because of the different methods used for data collection.

Slide 20:

For example, misophonia appeared frequently enough to deserve its own theme. One person said, *“The more I try to filter out an irritating sound (repetitive noises, loud music, someone chewing food etc) the louder it seems to get.”*

As another example, several respondents commented on the failings of standard audiological tests. This did not just refer to pure-tone audiometry but also tests that aim to be more sensitive. One respondent said, *“I had a*

hearing test for background noise interference that didn't diagnose mine because the test was flawed... it was not at all representative of the challenges I have in a real place like a cafe or large room."

Slide 21:

We also saw a huge number of references to difficulties with telecoms and broadcast audio. These are obviously technologies that have become increasingly important since the onset of the COVID-19 pandemic.

A typical response was "Phone/video calls - if you're speaking to me on the phone and there is any kind of noise going on in the room that I am in... I will really struggle to hear you."

Another person said, "Also television shows or radio: often a lot of background noise, many different accents, mouths are not clearly visible."

It is important to note that we did not ask directly about these modes of listening, yet many respondents spontaneously mentioned issues with these modes, which contrasts with our earlier interview data. This may reflect a self-selection bias in that people who struggle with telecoms/broadcast audio would have been unlikely to volunteer for our Zoom interviews.

Slide 22:

Our findings so far indicate listening difficulties with significant impacts. These have important implications for social participation and suggest potentially bi-directional interactions with emotional well-being, self-perception, and social fatigue. The above are potentially of great importance, due to social interaction difficulties being a core feature of autism and the high prevalence of secondary mental health problems in this group.

Slide 23:

Among our priorities are to help improve the quality of research in this field, both by ourselves and by others. Research needs to be adequately powered, with hypotheses based on autistic experience and data-collection procedures designed to suit both autistic and neurotypical participants. Differential measures should very systematically disentangle factors that might contribute to listening difficulty, and we need to allow for heterogeneity among autistic participants.

Slide 24:

One stride towards achieving these goals is research in genuine collaboration with the autistic community. Our autistic team members have been vital to everything we've done: design, outreach, analysis, interpretation, and more. They've shape study procedures to suit autistic participants and reduced the risk of neurotypical over-shadowing of autistic voices in qualitative data. And this depth of collaboration builds legacy, in that research experience both draws on **and develops** the research abilities of each collaborator.

Slide 25:

More concretely, we've designed two parallel studies on speech perception, one in the lab, one online. Both use contrasting listening conditions, testing for effects of various masker types, spatial information, predictability, and loudness of target speech. The lab study allows for greater range of contrasting listening conditions (and hence testing of a greater number of hypotheses) while the online study allows for a far larger sample size (and hence exploration of heterogeneity).

Slide 26:

One of our students is gathering data on coping strategies used by autistic people to manage listening difficulties. The self-report data presented earlier today indicate that strategies tend currently to be self-taught, achieved through trial and error, often into adulthood. Systematic compilation of successful strategies could be fed back to the community to support self-help and could support development of clinical guidance (which is currently lacking).

Slide 27:

We'll end with a few words from Leneh, who is an autism advocate and a very active member of Autism@Manchester: *"I know hundreds of autistic people and difficulty with auditory processing with background noise is the only universal characteristic I have been able to find."*

Thank you.