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Including young people severely affected by autism in scientific research

Iti Arora



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What are Autism Spectrum Conditions?

Autism changes the way people communicate and experience the world around them.

- Delayed or absent speech
 - Problems listening, concentrating and understanding
 - Frequent repetition of words or phrases
 - Difficulty expressing feelings or interpreting others' feelings
 - Difficulty making friends
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- Rituals or repetitive behaviors
 - Disliking changes to routines
 - Over or under sensitivity to sound, touch, taste, smell or light



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"Severely Affected"

Severely affected by autism or low-functioning autism

- ❑ Minimally verbal- 25-30%
- ❑ Autism + Intellectual Disability- 30-50%
- ❑ Autism with Regression- 32%

2% of neuroimaging research included people who were 'severely affected' (Jack and Pelphrey, 2017)

Anderson et al., 2007; Norrelgen et al., 2015; Rose, Trembath, Keen, & Paynter, 2016, Elsabbagh et al, 2012, Barger et al, 2013



Why is this population not studied?

- ❑ Recruitment challenges

- ❑ Methodological challenges

- Standard forms of assessment often do not apply (eg WISC, ADOS)
- Standard tasks are not appropriate

- ❑ Issues around behavioral compliance, anxiety

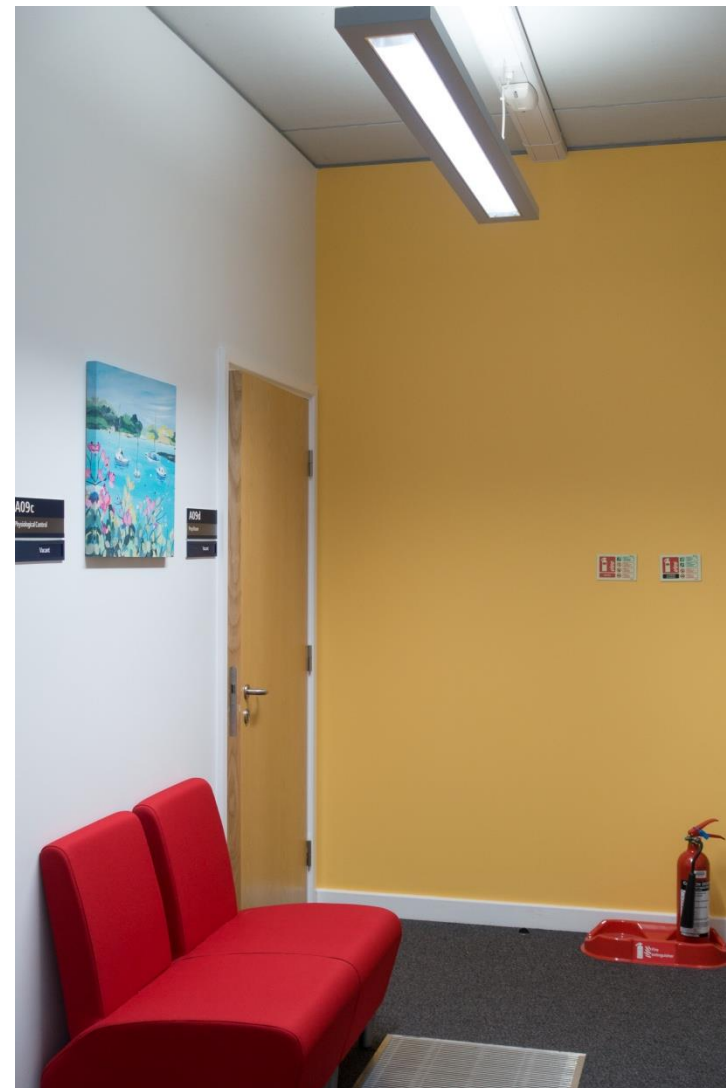
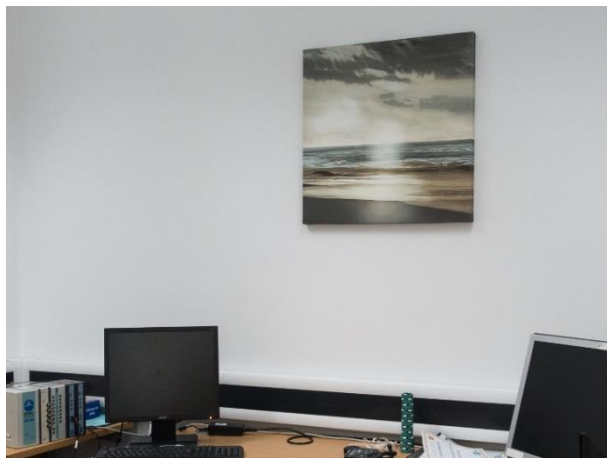


Step 1: Focus Group





Step 1: Focus Group





Step 3: Methodology

VIDEO for RECRUITMENT



Step 2: Recruitment

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CHILDREN and ADOLESCENTS (7-15 years old)
needed for the SAAND project (University of Nottingham)

We are studying attention in children with Autism (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD), and we are looking for children to come to the University of Nottingham and help us in our research.

We will measure your eye-movements, your brain activity, while you watch some images, videos or play some games on a computer.



You can participate in this study:
- If you are between 7 and 15 years of age
- If you have Autism and/or ADHD, but also if you don't have any of these conditions

If you want more information or you would like to participate in the study, you can contact us:

Alessio Bellato	Alessio.Bellato@nottingham.ac.uk
Iti Arora	Iti.Arora@nottingham.ac.uk
Mobile Number:	07806777705

Travel expenses will be paid to your parent, and an inconvenience allowance will be given to you.



We recruited from:

- Support groups
- NHS services
- Special Schools...
- Facebook

BUT NO LUCK...



Why is this population not studied?

☐ Recruitment challenges



Methodological challenges

- Standard forms of assessment often do not apply (eg WISC, ADOS)
- Standard tasks are not appropriate



Issues around behavioral compliance, anxiety



Why did we not have any success?

- Issues with words used in advertising?
- Topic not of interest to parents?
- Too daunting to take part?
- Too difficult to take time out?
- Lab based studies not appropriate?



SCIENTIFIC RESEARCH: WHAT ARE YOUR OPINIONS?

PARENTS of children with AUTISM (ASD) needed for a research project

Are you a parent of a child with a severe autism spectrum condition? We would like to carry out a short interview with you to find out whether you would allow your child to take part in scientific research and the reasons why you might not. The aim of this study is to find ways of making it easier for children on the autism spectrum to take part in scientific studies.





Thanks for your attention!
Any questions?

Dr Maddie Groom – School of Medicine
Prof Chris Hollis – School of Medicine
Dr Danielle Ropar – School of Psychology
Dr. Puja Kochhar- School of Medicine
Alessio Bellato – School of Medicine



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