

WHY DO ADULTS TAKE PART IN RESEARCH PROJECTS ABOUT AUTISM?



AIM



The aim of the research study was to find out what will encourage or discourage adults from taking part in research.

WHO WERE THE RESEARCHERS?



HOW WE DID THE RESEARCH

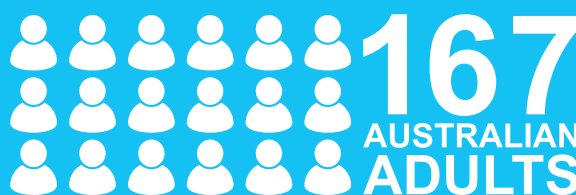


129 people took part in focus groups or interviews



38 people did an online survey

WHO TOOK PART?



167 Australian adults who were either:

- Diagnosed with high functioning autism/ Asperger's Syndrome (HFA/AS)
- Diagnosed with an autism spectrum disorder and an intellectual disability (ASD+ID)
- Carers of adults diagnosed with an autism spectrum disorder and an intellectual disability
- Neuro-typical adults were included so that we could compare what they thought, liked and disliked about taking part in research with the likes and dislikes of people on the autism spectrum.

ACKNOWLEDGEMENTS



Autism CRC and the research partners in this study sincerely thank the participants in this study for their time and their willingness to share their opinions and ideas. Without these contributions, this study would not have been possible.

FIND OUT MORE

You can get the full report of this study and an executive summary via the Autism CRC ASD Connect Hub at autismcrc.com.au/recruitmentreport

You can contact the researchers about this study via the study's

Project Leader: Dr Debra Costley, *Director Aspect Practice & Research Leader Autism Spectrum Australia (Aspect)*

Email: dcostley@autismspectrum.org.au

WHAT PEOPLE TOLD US

HOW WILL THIS RESEARCH HELP PEOPLE ON THE AUTISM SPECTRUM?

The findings of this study give researchers useful information about what will work and what will not work to attract people to take part in studies about the autism spectrum and then keep them interested and involved in the project. Autism CRC has used the recommendations of this study report to produce the Autism CRC Inclusive Research Practice Guide 7, advising researchers how to work with people on the autism spectrum as research participants, taking into account both their strengths and areas where they may need support.



WE ARE ALL DIFFERENT, WE ARE ALL INDIVIDUALS

We found that the reasons why people take part in research about the autism spectrum, what they like and dislike about taking part in research, and what will make it easier or more difficult for people to take part was different for each of the four groups of people who took part in the study.

The information we gathered also showed us that these things were different for individual people within each of the four groups.



THINGS THAT MAKE IT DIFFICULT TO TAKE PART IN A RESEARCH PROJECT

- Time and the travel required
- Research must be sensitive to individual preferences



WHY PEOPLE WANT TO TAKE PART IN RESEARCH ABOUT AUTISM SPECTRUM

All participants:

- Helping to make things better for people on the spectrum
- Helping to develop practical programs and initiatives
- Increasing the acceptance and understanding of people on the spectrum by others
- Creating more opportunities for people to have a fulfilled life as part of the wider community



Participants on the Spectrum:

- Being valued as equal partners and given the opportunity to contribute to all aspects of the study
- Having their voices heard and acted upon, and to be able to contribute across the full range of their capabilities

THINGS THAT MAKE IT EASIER TO TAKE PART IN A RESEARCH PROJECT

- More choices around how to take part:
 - Online
 - Interview by phone
 - Face to face interview
 - Focus group
- Small gifts, vouchers or money for taking part was meaningful for some but not all
- Reimbursement of travel costs or babysitting

