



Optimising the recruitment and retention of adults for longitudinal autism spectrum research: a mixed methods study

EXECUTIVE SUMMARY

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TERMINOLOGY AND ABBREVIATIONS

1. A number of participants in this study rejected the use of the term 'disorder' to describe their experience of autism. For this reason, the authors of this report have chosen to use the terminology '*the autism spectrum*', '*people on the autism spectrum*' and '*autism spectrum research*' when referring to the conditions described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as '*autism spectrum disorder*'.
2. This report adopts the scientific convention of using abbreviations for each of the categories of participants who took part in this study; for example:
 - Participants with high functioning autism/Asperger's Syndrome (HFA/AS)
 - Participants on the autism spectrum with an intellectual disability (ASD+ID)
 - Carers of participants on the autism spectrum with an intellectual disability (Carers)
 - Neuro-typical participants (NT).

This use of abbreviations is not a 'labelling' of any individual participant or group of participants. It has been adopted for brevity, clarity in reporting and ease of reading.

THE COOPERATIVE RESEARCH CENTRE FOR LIVING WITH AUTISM SPECTRUM DISORDER (AUTISM CRC)

The Cooperative Research Centre for Living with Autism Spectrum Disorder (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole of life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide practical solutions for governments, service providers, education and health professionals, families and people with autism. Autism CRC aims to solve complex problems with innovative solutions that can only come from having the best minds collaborating as one team - the Autism CRC Team www.autismcrc.com.au

PURPOSE OF THIS STUDY

Research projects in the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) Core Program 3 *Adults with Autism - Finding a Place in Society* will target younger, middle aged and older adults on the autism spectrum and matched neuro-typical participants.

The recruitment and retention of adults on the autism spectrum is likely to pose some difficulties; a particular challenge will be to recruit participants from the autism spectrum who are willing to be tracked over four years.

To date, an understanding of factors that influence the recruitment and retention of adult participants for autism spectrum research is unexamined in any detail in the research literature.

AIM OF THIS STUDY

The aim of this study was to identify motivators and barriers to participation in longitudinal research for adults (both on and not on the autism spectrum) with the purpose of informing the design of recruitment and retention strategies for future CRC Program 3 research projects.

STUDY DESCRIPTION

Using both quantitative and qualitative methods for data collection and analysis, the study was conducted from November 2013 to July 2014, with data collection occurring between May and July 2014, across four Australian states, as a collaboration of four essential participants in the Autism CRC:

- Autism Spectrum Australia(Aspect), as lead organisation - New South Wales
- Olga Tennison Autism Research Centre, La Trobe University - Victoria
- Curtin University - Western Australia
- The University of Queensland - Queensland.

Using a variety of recruitment methods, the researchers enlisted a total of 167 participants into the study.

- 129 participants took part in 17 focus groups and in 17 individual or small group interviews, conducted in Brisbane, Sydney, Melbourne, Bendigo and Perth.
- A further 38 participants completed an online survey, which incorporated the same questions and discussion points used in the focus groups.

All participants were adults (defined for this study as aged 18 years and over) who were resident in Australia.

Participants were recruited in four categories:

1. Adults diagnosed with high functioning autism/Asperger's Syndrome
2. Adults diagnosed with an autism spectrum disorder and an intellectual disability
3. Carers of adults diagnosed with an autism spectrum disorder and an intellectual disability
4. Neuro-typical adults.

DATA ANALYSIS

Quantitative data collected via participants' responses in focus groups via a card sort exercise, questionnaire and discussion and via the online survey were collated and tabulated and a frequency analysis produced for each question asked of participants. The audio recorded commentaries and written extended responses of participants formed the qualitative data, which was transcribed and coded for thematic analysis.

SUMMARY OF FINDINGS

The study found that the factors influencing participation in longitudinal autism spectrum research can be categorised as:

- Motivators - the reasons why I participate; the outcomes I am seeking through my participation
- Inhibitors - factors that discourage or prevent me from taking part
- Enablers - factors that make it easier for me to take part.

The results indicate that the motivators, inhibitors and enablers of participation differ markedly between (and in some cases within) each participant category. For this reason, results for each participant category are summarised in the tables below:

Table 1 Summary of identified motivators, inhibitors and enablers, common to all participant categories

Table 2 Summary of identified motivators, inhibitors and enablers, by participant category

ONE SIZE DOES NOT FIT ALL

Some factors identified as motivators for certain participants were found to be either inhibitors or enablers for others. The most noticeable example of this was participants' divergent attitudes about any social interaction. For some participants, the opportunity for social interaction was a motivator.

For others, any requirement to mix with other people was found to make them less likely to participate in a research study.

MOTIVATORS

While helping others was found to be a key motivator across all participant categories, it was clear that participants also sought 'personal benefit' from their participation.

What participants considered to be a 'personal benefit' differed markedly between participant categories. For adults on the autism spectrum, 'personal benefit' was viewed through the lens of their individual preferences and needs, and their desire for improved opportunities to engage in all aspects of life in meaningful and rewarding ways. Carers of adults on the autism spectrum interpreted 'personal benefit' in terms of a benefit to their child rather than to themselves.

The results provided evidence that most participants were keen to contribute to and engage with autism spectrum research projects that will lead to practical programs and initiatives to enable people on the spectrum to enjoy a greater degree of acceptance, involvement and opportunities to lead fulfilled lives in the wider community.

Participants indicated a desire, in varying degrees and various ways, to draw comfort, a sense of worth and inspiration from belonging to a research project community. Being kept up-to-date with the progress of the research project and how the participant's input has contributed to the research outcomes was found to be an important part of engendering this sense of belonging.

INHIBITORS

Key inhibitors to participation were found to be the inconvenience of time and travel required; and any insensitivity shown in the research process to an individual's personal needs and preferences for engaging with the world and others.

ENABLERS

The study found that maximising choice for all aspects of participant involvement can act as a vital enabler of participation, as this choice allows for the breadth and idiosyncratic nature of the personal preferences and needs of individuals across the spectrum.

Participants also indicated that the reimbursement of any out-of-pocket expenses they incurred as part of their participation (such as travel costs) is an effective and valued enabler of their participation.

EXTRINSIC REWARDS

While participants welcomed any acknowledgement of the time and effort that they may contribute to a research project, the study found that the use of financial and other extrinsic rewards is likely to be problematic as a means of encouraging people to participate in longitudinal autism research studies.

The study found that while extrinsic rewards were an enabler to taking part for some participants, others participants considered that extrinsic rewards would act as an inhibitor to their participation. Thus, in seeking to optimise participation, the use of financial and other extrinsic rewards needs to be handled with care and sensitivity.

TABLE 1. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS COMMON TO ALL PARTICIPANT CATEGORIES

Motivators – WHY WE WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE US	Enablers – WHAT WILL MAKE IT EASIER FOR US	Motivator/Enabler for some but Inhibitor for others
<p>Opportunities to contribute to research that will effectively advance the world’s understanding of autism and acceptance of people with autism, and will provide more opportunities for people with autism</p> <p>Being kept up-to-date with the research project, to know progress and outcomes</p> <p>Belonging to a project/community/sense of connection to the project</p>	<p>Travel- time, distance, cost, hassle</p> <p>Sensitivity re psychological/mental health issues</p>	<p>Choice and flexibility for all aspects of my involvement, e.g.:</p> <ul style="list-style-type: none"> – how, when and where to participate – involvement in social interactions – opt-in for communications – options for mode of communication, i.e. digital/print – opt in for rewards/incentives, publicity, disclosure – options for any rewards/incentives <p>Extrinsic rewards as acknowledgement and show of appreciation for my contribution and my time given</p> <p>Monetary reimbursement for the costs of participation, e.g.: travel, child-minding expenses</p> <p>Reminders for research project activities</p>	<p>Any requirement for social interaction</p> <p>Extrinsic gifts, e.g., branded gifts, payment for enlisting friends, birthday cards</p> <ul style="list-style-type: none"> – <i>Inhibitor for some:</i> perceived as a waste of research resources and/or tokenism; – <i>Enabler for some:</i> perceived as a thoughtful and kind personal touch

TABLE 2A. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR PARTICIPANTS WITH HIGH FUNCTIONING AUTISM/ASPERGER'S SYNDROME

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
<p>Engaging with and contributing to research that will effectively advance the world's understanding of autism so as to improve the opportunities for adults living with autism to engage in all aspects of life in meaningful and rewarding ways and be adequately recognised for their abilities and contributions</p> <p>Opportunities to have my say, to have my voice heard, to explain myself fully, to be understood</p> <p>Opportunities to participate as an equal, skilled and valued partner in the research</p> <p>Opportunities to interact and communicate with the research team, about autism spectrum research and the research project</p> <p>Being kept up-to-date with the research project, to know progress and outcomes, and to see and compare others' responses in the research study with my own</p> <p>Opportunities to engage and exchange views and information within an autism spectrum community: e.g. via project website</p>	<p>“One size fits all”</p> <p>Insensitivity to autism spectrum issues unsuitable venues (noise, light, sensory issues) events with large numbers of people neuro-typical misinterpretation or misunderstanding of autism spectrum viewpoints modes of data collection that do not allow for autism spectrum concerns, AD cognition, autism spectrum communication styles, autism spectrum social preferences e.g. labelling of people on spectrum as having a disorder</p> <p>Tokenism, e.g.:</p> <ul style="list-style-type: none"> – birthday cards – (for some) menial tasks – gifts, esp branded items – payment for enlisting friends <p>(Perceived) waste of research resources, e.g.:</p> <ul style="list-style-type: none"> – gifts, esp. branded gifts – payment for enlisting friends <p>Travel</p> <ul style="list-style-type: none"> – distance and time – cost – mode – anxiety 	<p>Choice in all aspects of my involvement to cater for my individual preferences, e.g.:</p> <ul style="list-style-type: none"> – how, when, where to participate – involvement requiring social interactions – opt in for communications – options for mode of communication, i.e. digital/print – opt in for rewards/incentives – options for any rewards/incentives. <p>In all aspects of my engagement with the research process, respect is accorded to my viewpoints, individual needs, concerns, ways of being; and my capacity to contribute as a valued and active partner in the research</p> <p>Extrinsic rewards as acknowledgement and show of appreciation for my contribution and time</p> <p>Monetary reimbursement for the costs of participation, e.g. travel, child-minding expenses</p> <p>Access to research team, to clarify my responses to research questions and methods</p> <p>Reminders for activities</p> <p>Venues cater for autism spectrum sensitivities</p> <p>Modes of data collection are sensitive to autism spectrum cognition, communication styles, social interaction preferences, e.g. researchers trained in autism spectrum interactions and issues</p>	<p>MOTIVATES SOME, INHIBITS OTHERS</p> <p>Any requirement for social interaction Social interaction in large groups</p> <p>FOR SOME ONLY, not an issue for others</p> <ul style="list-style-type: none"> – Disclosure – Publicity – Mental health – Physical health

TABLE 2B. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR PARTICIPANTS WITH AUTISM AND AN INTELLECTUAL DISABILITY

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
<p>Explicit acknowledgement of and recognition for me (that I am important and valued), e.g.:</p> <ul style="list-style-type: none"> – birthday card/gift – gifts, rewards, incentives that are specific to my personal interests – newsletter article and photo about me <p>Knowing and finding out what is happening (now and next) and who is doing what</p> <p>Opportunities to make friendships</p> <p>Participation with/by a friend or family member</p> <p>Research will lead to a greater acceptance and understanding by the general public of ASD+ID people and my needs</p> <p>(Carer): Opportunities for my ASD+ID children to learn more about themselves</p> <p>(Carer): Opportunities for my ASD+ID children to acquire work-related skills and experience</p>	<p>The project does not allow or enable my carer to participate with/for me</p> <p>Research does not cater for participation that fits my routine, cognition or communication skills</p> <p>No established relationships of trust with research team</p> <p>(Carer) Any potential for harm to self-esteem or sense of safety for ASD+ID child</p> <p>Mental health</p> <p>Travel and travel costs (a carer issue, not my issue)</p> <p>Research activities disrupt my regular routine</p>	<p>ESSENTIAL Support and participation of my Carer</p> <p>Research is designed and conducted with sensitivity to my particular needs:</p> <ul style="list-style-type: none"> – Flexibility in how, when and where I participate – Researchers have established relationships of trust with me – Project offers the capacity to fit the research activities into the participant’s normal daily routine and environment where a sense of security, safety and calm for me is assured. – Research is conducted in my own environment <p>Carer can contact research team for: project liaison, project information, explanations about my needs</p> <p>Adequate time to complete activities and provide responses</p>	<p>FOR SOME ONLY, not of interest for others</p> <ul style="list-style-type: none"> – Social interaction with others similar to me

TABLE 2C. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR CARERS OF ASD+ID ADULTS

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
<p>Finding knowledge and practical solutions that will improve the well-being of and life choices for my ASD+ID child and for other people</p> <p>Being kept up-to-date with Information about:</p> <ul style="list-style-type: none"> – autism spectrum knowledge and ASD+ID services – the research project <p>Opportunities to share information and experiences with others in a similar situation: e.g.:</p> <ul style="list-style-type: none"> – drinks function – project website 	<p>Carer responsibilities – time and routine</p> <p>Travel – carer responsibilities</p> <p>My sensitivity re my child’s psychological/mental health issues and the potential for my child to be upset by the research process</p>	<p>Choice of how, where and when to participate, to fit in with carer responsibilities and routine</p> <p>Reimbursement of costs of participation, e.g.:</p> <ul style="list-style-type: none"> – travel – child-minding expenses <p>Cash payments and/ vouchers</p> <p>Communication, liaison, reminders organised by the research team</p>	<p>FOR SOME ONLY</p> <ul style="list-style-type: none"> – Negative discussions about ASD+ID – Lack of regular access to telephone or internet

TABLE 2D. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR NEURO-TYPICAL PARTICIPANTS

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
<p>An easy way to do something to help others, esp. my family members living with autism</p> <p>Opportunities to learn more about the autism spectrum, especially how to understand, help and interact with my family members living with autism</p> <p>Opportunities for learning for self-awareness and personal development</p> <p>Seeing the outcomes of their own contributions and comparing these to others</p> <p>Belonging to a project/community/sense of connection to the project</p> <p>Acknowledgement and appreciation of my contributions</p>	<p>Inconvenience: e.g.:</p> <ul style="list-style-type: none"> – time for participation – travel time, distance, hassle – requirement to participate in a particular way <p>Travel</p> <ul style="list-style-type: none"> – distance – time – cost – mode – inconvenience <p>Publicity for self</p>	<p>Choice for how, when and where to participate</p> <p>Reimbursement of travel costs</p> <p>Choice for project communications – format and opt-in/out</p> <p>Single hub for all information and liaison for the project e.g. project website</p>	<p>MOTIVATOR OR ENABLER FOR SOME ONLY</p> <p>Extrinsic rewards and incentives as acknowledgement and appreciation of my contributions, e.g.:</p> <ul style="list-style-type: none"> – gift vouchers – gifts - consumables <p>ENABLER FOR SOME, INHIBITOR FOR SOME</p> <p>Branded gifts, payment for enlisting friends, birthday cards</p> <ul style="list-style-type: none"> – <i>Inhibitor for some:</i> perceived as a waste of research resources and/or tokenism; – <i>Enabler for some:</i> perceived as a thoughtful and kind personal touch <p>FOR SOME ONLY</p> <p>Opportunities to participate with a friend or relative</p> <p>Opportunities to be involved with the project behind the scenes</p> <p>Sharing information and experiences wrt my autism spectrum child/relative</p>

KEY INSIGHTS FROM THE RECRUITMENT PROCESS

Key findings from the recruitment process employed in this study are also applicable to optimising recruitment for future autism spectrum research studies:

- The most challenging participant category to recruit into the study was for participants on the autism spectrum with an intellectual disability.
- The recruitment of participants on the autism spectrum with an intellectual disability first required the recruitment of their carers, as co-participants in the study.
- Carers of participants on the autism spectrum with an intellectual disability were most effectively identified and reached through disability networks, rather than through the autism community.
- Recruitment communications via social media, through the many autism support networks, support groups and service providers was an effective initial step in recruiting participants with high functioning autism/Asperger's Syndrome.
- The two methods found to be effective in recruiting neuro-typical participants into this study were via social media, including through autism support networks, support groups and service providers; and snowballing.
- With the study implementing its participant recruitment through four research partners in different locations around Australia, co-ordination and consistency proved critical to successful participant recruitment. This included the development and use of a single set of communication materials with consistent text, content, messages and visuals providing a clear and distinctive project branding; together with a co-ordinated approach and schedule to recruitment methods.

This co-ordinated approach, developed and implemented by the lead research partner in conjunction with the other research partners, ensured a cost-effective use of resources in recruitment and consistent recruitment communications and branding for the study net across all locations and partners.

IMPLICATIONS FOR FUTURE STUDIES

Based on the findings of this study, the following measures and approaches are recommended for consideration in the design and implementation of future research projects in the Autism CRC Program 3, so as to optimise participant recruitment and retention in these projects:

SHOW SENSITIVITY TO THE FULL SPECTRUM OF INDIVIDUAL NEEDS AND PREFERENCES OF ALL PARTICIPANTS

To maximise the levels of both comfort and satisfaction for the broadest range of participants while taking part in the study:

- Purposefully design and implement the study to be sensitive to the very broad spectrum of all potential participants' differing communication, social and cognitive skills and preferences; lifestyles; and sensory needs.
- Take into account the incompatibility of the preferences for some participants with those of others.

The particular requirements and preferences identified for each category of people who participated in this study are listed above in *Summary of motivators, inhibitors and enablers, by participant category*.

Practical recommendations to implement this sensitivity to the spectrum of individual's needs and preferences include:

- Select event venues that cater for sensory issues experienced by some autism spectrum people, such as discomfort with excessive noise, light and crowds.
- Offer options for data collection that do not require face-to-face communication or travel.
- Provide the facility for participants to give additional explanations for any responses to questions.
- Provide the facility for participants to give feedback to the research team on research methods.
- Eliminate ambiguity and potential for multiple meanings or interpretations in any communication.
- Establish relationships of trust with participants with autism and an intellectual disability prior to any recruitment or data collection.
- Provide the option to come to the home environment of participants with autism and an intellectual disability to collect data.
- Provide in-time reminders and information for any events and activities.
- Avoid any stereotyping of the attributes of people with autism.

In addition, it is appropriate that all researchers and other staff involved in the design and administration of Autism CRC Program 3 research projects have training in and/or knowledge of the lived experience of people living on the autism spectrum.

MAXIMISE THE RANGE OF OPTIONS FOR PARTICIPANTS TO ENGAGE WITH THE RESEARCH

Maximise the range of options available to participants for engaging with the project, and clearly communicate these options to participants, such as:

- how, when and where to participate
- a choice of modes of participation that:
 - provide exposure to social interactions
 - do not require any social interaction
- opt-in/out to receive communications
- options for preferred format for communication and materials: e.g. digital/print; telephone/email/post/face-to-face
- opt-in/out to receive rewards and incentives
- options for different types of rewards and incentives
- a range of options for additional involvement in the research project that are appropriate for and sensitive to different participants' interests, capacity and skills.

TAILOR RECRUITMENT METHODS TO MOST EFFECTIVELY REACH DIFFERENT TYPES OF PARTICIPANTS

- To most effectively reach and appeal to each specific category of participants, tailor the community networks, methods, communication channels and messages that are used for participant recruitment to match the profile of each participant category.

KEY-IN THE PARTICIPANTS' MOTIVATIONS FOR ENGAGEMENT, USING EFFECTIVE RECRUITMENT AND RETENTION COMMUNICATIONS

- Clearly communicate the purpose and the pragmatic, results-oriented nature of the Autism CRC Program 3 research projects.
- Provide the option to receive ongoing updates on the progress of the research project and a final report on the study results and outcomes, with a focus on pragmatic programs to assist people with autism that are being or will be developed and implemented as a result of the study findings.
- Provide feedback to participants about the impact that their contribution has made to autism spectrum research.
- Provide participants with a means of connecting with and learning about the wider Autism CRC program and community.
- Each category of participants will also be most responsive to recruitment messages that are tailored to appeal to their specific key motivations for participating in longitudinal autism spectrum research.

TAKE CARE IN OFFERING EXTRINSIC REWARDS FOR PARTICIPATION

- Offer a choice of either cash (or pre-paid credit card) or a range of vouchers, for a small value, such as \$30 for a two hour contribution, and offer these clearly as acknowledgement and appreciation of the participant's contribution.
- As an alternative to accepting cash or a gift voucher, also provide the option for participants to donate the value of any reward to either a CRC research project or an autism spectrum related charity.
- Exclude birthday cards, 'tell-a-friend' rewards and gifts (especially branded items such as pens, hats and mugs) from any incentive program, as these types of rewards are likely to generate a negative reaction with many participants with high functioning autism/Asperger's Syndrome, carers and neuro-typical participants and may represent a 'waste' of resources.
- The exceptions to this are:
 - a) if the project is dealing solely with participants with autism and an intellectual disability, or
 - b) if the researcher has established a personal one-on-one relationship with the individual participant.

OFFER REIMBURSEMENT FOR TRAVEL, FOR A FIXED AMOUNT

Offer participants a standard, flat payment for the travel cost of each round trip they make to participate in a project activity (i.e., an amount that is not linked to the individual distance travelled or fares/petrol purchased, but is the same value for all participants), paid to participants via either a pre-paid credit card, a generic voucher or direct bank transfer.

PROVIDE CONNECTION AND A SAFE, CARING COMMUNITY FOR PARTICIPANTS

Across all categories in this study, participants expressed a sense of satisfaction in belonging to a community of like-minded people with similar interests with whom they could share and exchange information, ideas and narratives about their life experiences.

Initiatives and activities that offer such participants a sense of belonging to a community of likeminded people with similar interests with whom they can share and exchange include:

- A secure project website that:
 - provides a single, central hub for all project information, communications and activities;
 - engenders a sense of belonging and membership; and
 - provides opportunities for online interaction between participants, and also with the research team;
- Task-oriented forums, discussion groups and social groups where participants can interact with each other and to meet with and hear from the research team, with a focus around topics related to the autism spectrum or autism spectrum research;
- Invitations to join a group of participants at social events conducted by autism spectrum organisations, such as art exhibitions and entertainment/performances. Projects could consider offering participants either free or discounted entry to such events, as part of any reward program for the project.



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