



Autism CRC Research Academy

EXECUTIVE SUMMARY

Prof Sylvia Rodger AM
Ms Judy Brewer AO
Dr Olivia Gatfield
Dr Wenn Lawson
Dr Kate van Dooren

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AutismCRC
Research Academy

Autism CRC Ltd *Cooperative Research Centre for Living with Autism*

Level 3, Foxtail Building, Long Pocket Campus, The University of Queensland, Q 4072
80 Meiers Road, Indooroopilly
PO Box 6068, St Lucia Q 4067 | +61 7 3377 0600 | info@autismcrc.com.au
ABN 55 162 632 180

autismcrc.com.au



Australian Government
Department of Industry,
Innovation and Science

Business
Cooperative Research
Centres Programme

Autism CRC Research Academy

Prof Sylvia Rodger AM

Director of Research and Education, Autism CRC

Ms Judy Brewer AO

Chair of the Board, Autism CRC

Dr Olivia Gatfield

Project officer, Autism CRC

Dr Wenn Lawson,

Other participant, Autism CRC

Dr Kate van Dooren

Postdoctoral Fellow, Autism CRC and Queensland Centre for Intellectual and Developmental Disability (QCIDD), The University of Queensland

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Note on terminology: It is acknowledged that members of the autism community have varied views about appropriate terminology, however, consistent with Autism CRC style guide and discussions with our Academy members, the terms , 'on the autism spectrum' and 'on the spectrum' will be used in this report.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (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 evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people with autism.

autismcrc.com.au



PURPOSE OF THIS STUDY

The purpose of Autism CRC's Research Academy is to build the capacity for co-production/ peer research within the autistic and research communities in Australia. The purpose of this study was to evaluate the effectiveness of the Researching Autism Together Workshop, the primary vehicle for advancing co-production proficiencies.

STUDY DESCRIPTION

To build capacity for peer research, the Researching Autism Together Workshop was delivered in October 2015 to adults on the autism spectrum (n=14 attending for 5-days) and autism researchers (n=14 attending for 1-day). The specific objectives of the workshop were for participants to:

- learn the specific skills needed to be a peer researcher;
- develop an understanding of the benefits of peer research;
- learn about effective peer research;
- network with potential peer researchers from around Australia; and,
- gain membership into the Research Academy.

To determine the effectiveness of the workshop, survey and focus group data was collected from participants on the spectrum (n=14) who attended the workshop for 5-days. In addition, survey data were collected from autism researchers (n=13) who attended the workshop for 1-day.

n.b. a full description of workshop development, recruitment, delivery and planning can be found in the Autism CRC Research Academy Final Report (autismcrc.com.au/academyreport).

SUMMARY OF FINDINGS

Survey data collected from adults on the spectrum (n=14) and autism researchers (n=13) showed high approval ratings. All participants rated the workshop as 'good' and 'excellent' and all participants would recommend the workshop to others. Analysis of data also indicated an increase in *competence* to engage in peer research and, for researchers, *likeliness* to engage in peer research. The majority of adults on the spectrum indicated increased competence to undertake all aspects of peer research.

Analysis of qualitative data collected from adults on the spectrum emphasised a highly successful workshop which exceeded their expectations. It was identified that throughout the workshop their lived experience was "truly valued" and their needs were considered and catered for. With regard to workshop *content and methods* it was identified that:

- The content was pitched at the right level indicating prior knowledge surveying as appropriate;
- Less content would have allowed for more group interaction, which was preferred;
- Having a question and comments box enabled people to voice their opinion and ask questions; and,

- Having the project team perform the first role play alleviated anxiety around their involvement in role play activities.

With regard to *format*, it was identified that:

- Breaks longer than 10 minutes and 60 minutes for lunch were required for some participants to maintain energy levels;
- Engagement in the group may have been lessened for those who lived locally so were not staying at the workshop venue; and,
- Having only 1-day overlap with autism researchers was not enough time to enable interaction and engagement.

IMPLICATIONS/RECOMMENDATIONS

Evaluation data as well as reflections provided by project advisory group members (n=6, including four people on the spectrum) and the project team (n=4, including two people with autistic lived experience) provided suggestions for future practice. These relate to content, methods and processes, preparation, and format.

Content, methods and processes

- Future workshops should provide less content to allow more group interaction and discussion, or allocate time to enable expression without impinging on content delivery;
- For the purpose of emotional support, enable participants to 'vent' to appropriate people if they wish to - such as by providing blue dots for participants to place on their nametag if they are willing to have others 'vent' to them.

To enable networking between researchers and people on the spectrum that is facilitative of peer research:

- More than one contact day is necessary;
- Researchers to complete readings about autism culture prior to attending to provide them with an understanding of the alienation felt by the autistic community so that (a) they can appropriately enter the 'autistic space' and (b) aid them in more effective peer-research;
- In addition to providing photos and bios of autism researchers, provide participants on the spectrum with some personal information on the researchers— potentially a video clip. Additionally, provide researchers with bios of those on the spectrum;
- Prepare researchers for supportive processes used at the workshop, e.g. stickers to indicate desired level of communication, and encourage them to use this system;
- Debrief researchers on the terminology used by the attendees on the spectrum to describe autism and the autism community;
- Ensure the function room is set appropriately to enable open sharing and discussion- not in lecture style;
- Consider activities that are facilitative of building trust and rapport, rather than 'question and answer' style.

Preparation

- Prepare participants on the spectrum for what it is like being in a space which in which others on the spectrum are the majority (termed 'autistic space'). For example, that they can expect open sharing of personal experiences and thoughts.
- Participants on the spectrum need to be informed of the potential 'emotional cost' of attending, in terms of emotional, physical and social loads.
- Provide participants on the spectrum with an understanding of potential isolation and exhaustion they may experience on returning home after workshop completion. Also, to help them prepare for this likelihood during the workshop.

Format

- Consider format of workshop delivery in terms of enabling content delivery required for effective peer research, potential participant fatigue and the power of 'autistic space'. Potential formats include combinations of face-to-face workshop, virtual meetings and online modules.
- Provide participants with opportunities for peer research immediately after workshop delivery to maintain momentum and engagement.