



Research Program 2020

Evaluation Report

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Research Program 2020

Evaluation Report

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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- Prof Liz Pellicano
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We also wish to extend our thanks to the 21 Program participants. Their dedication and willingness to change the status quo of autism research is truly remarkable.

Autism CRC

Autism CRC are the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

The Sylvia Rodger Academy is an initiative of Autism CRC. The Academy delivers nationwide programs aimed at empowering autistic adults. Its vision is to see autistic people thriving through discovering and using their strengths.

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1. Background

The mission of Autism CRC is to initiate, co-produce and translate collaborative research and best practice guidance that delivers positive change for all autistic people. To support the co-production of research and its translation, Autism CRC developed a number of resources including the Autism CRC Statement on Inclusive Practices and a series of Inclusive Research Practices Guides and Checklists.

With the aim of further enhancing the uptake and quality of co-production, participatory research and inclusive research practices nationally and internationally, the [Participatory and Inclusive Autism Research Practice Guides](#) were released in 2021. To further facilitate the

implementation of such practices, Autism CRC continues to support capacity building through the Sylvia Rodger Academy Research Program.

The Sylvia Rodger Academy first delivered the Research Program to autistic individuals and autism researchers in 2015 and 2017. While the objectives of the Program have not changed, the delivery methods and format have evolved over time. To highlight, the 2015 delivery was a 5-day residential workshop for autistic individuals, including autism researchers for 1-day, and one written task for autism researchers. In contrast, the 2020 iteration, to which this report relates, included: seven online modules and sessions; a 3.5-day residential workshop including autism researchers for 1.5 days; a practical component; and, additional written submissions for autism researchers. As the Program was delivered during the COVID-19 pandemic, online masterclasses and structured discussions were also added as a component to maintain engagement and momentum until the final element of the Program - the residential workshop - could be held.

This document outlines the various elements of the 2020 delivery for the two streams (being autistic participants and autism researchers), the support practices that were utilised, and provides evaluation of the components.

2. Objectives and governance

The objectives of the Research Program were for participants to:

- learn and further develop the skills for co-production/participatory research
- increase their engagement in co-production/participatory research
- network with potential co-producers from around Australia, enabling them to share experiences, follow up and share opportunities
- enhance their practical knowledge and experience to build and reinforce skills
- develop an understanding of the benefits of co-production/participatory research
- gain membership into the Sylvia Rodger Academy.

To ensure that the Program elements met these objectives, the project was governed and delivered by an autistic majority Project Team, including graduates from the 2015 and 2017 Programs, and led by an autistic Project Officer.

3. Participants and program elements

3.1 Participants

Participants in the 2020 Research Program were 10 autism researchers and 15 autistic adults. Program delivery was impacted by COVID-19 and accordingly, a number of participants were not able to complete the Program. Eight autism researchers and 13 autistic adults completed the Program.

A number of autism researchers also identified as autistic, with decisions around which stream to apply for based on individual's level of knowledge of research practices and processes.

3.2 Program elements

Autistic participant stream

The elements of the Program for this stream were:

1. **Modules and online sessions.** The purpose of this element was to enable participants to increase their knowledge of research practices and processes. Participants were provided with seven modules in a custom e-learning environment, on the following topics.
 - Introduction to Autism CRC and Inclusive Practice
 - Introduction to Ethics
 - Introduction to Participatory Research
 - Introduction to Quantitative Research
 - Introduction to Qualitative research
 - Introduction to Mixed Methods Research
 - Introduction to Research Dissemination.

The modules included written content, videos, review activities and additional readings. Online sessions for each topic were facilitated by a member of the Project Team and aimed to support participant knowledge, provide opportunity for questions to be answered and facilitate connection and networking. The sessions were recorded and available to participants who were unable to attend.

2. **Practical component.** The purpose of the practical component was to facilitate participants understanding of co-production in action, and to provide the opportunity to gain skills and

knowledge relevant to their personal research or co-production goals. Accordingly, this Program element comprised of:

- a) In-depth investigation of the lifecycle of a co-produced research project. Participants watched custom pre-recorded videos and read sections of the related journal article before participating in online sessions to discuss. To enable in-depth discussion, the online sessions utilised small group break out rooms.
- b) A self-directed component in which participants could choose from a variety of activities relevant to their research journey. Activities included: attending online conferences; reading research in their area of interest; working with researchers engaged in co-production; completing a short online course; and, emailing researchers working in areas of their research interest to be considered for co-production/participatory research opportunities.

3. Masterclasses and Structured Discussions. The purpose of this element was to provide connection and upskilling in topics of interest to participants. This was not an intended element of the Program, however, was added to maintain engagement during the pandemic until a residential workshop could be held. It was not a formal part of the Program, with participation being optional.

Structured discussion topics chosen by participants included: executive functioning and co-occurring conditions; self-care, sleep and sensory overload; and, autistic identity and masking. Masterclasses included topics such as: research translation and co-design; research on autistic burnout; and the LGBTQIA+ community and autism research considerations.

4. Residential Workshop. The purpose of the workshop was to upskill participants in practical skills for co-production/participatory research, network with potential co-producers from around Australia, and share experiences and knowledge. The residential workshop was held over 3.5 days in Brisbane, with session topics and format for delivery as listed in Table 1.

To ensure participant engagement in the workshop, a number of support practices were implemented. These included: having four designated support staff; a variety of inclusive and accessibility practices; inclusion of a therapy dog; and, a preparation and wellbeing toolkit. The later was developed with a clinical psychologist to enable participants to explore the components of the Program, create a plan to reduce concerns and prepare, and develop a crisis plan to be enable the Project Team to support people in their chosen way, if required.

Table 1: Workshop topics, allocations, format and session attendees

Topic	Format of Delivery	Attendees	Time allocation (minutes)
Experiences of Research	Facilitated group discussion	Autistic participants stream	60
Contributing to Co-production/Participatory Research	Presentation	Autistic participants stream	60
Communication and Power Balance in Research	Presentation and discussion	Autistic participants stream	60
Participating in Research Opportunities	Presentation	Autistic participants stream	60
Q&A Panel with autistic leaders	Facilitated group discussion	Autistic participants stream	60
Diamond Ranking Activity	Small group activity and presentations	Autistic participants stream Autism researchers stream	120
Research Trends - Presentation	Presentation	Autistic participants stream Autism researchers stream	60
Participatory Research/Co-Production	Presentation and small group activity	Autistic participants stream Autism researchers stream	60

Autism researcher stream

The elements of the Program for the autism researcher stream were:

1. **Written submissions.** The purpose of this was to upskill autism researchers on the neurodiversity paradigm, lived-experience of autism and co-production/participatory research. Participants were provided with a list of related articles, blogs, videos and resources and were required to submit task responses. The tasks centred on a) articulation of what a deeper understanding of autism and neurodiversity means for them as a researcher, and b) applying co-production and/or a participatory research framework to research that they had conducted or were undertaking.
2. **Masterclasses.** The purpose was to provide upskilling in topics pertinent to autism research. This was an optional component, and was included to maintain engagement through the pandemic. Topics included: autistic community perspectives; setting up and managing advisory groups and employing autistic consultants; and, the LGBTIQ+ community and autism research considerations.
3. **Residential Workshop.** The purpose of the workshop for this stream was to enable researchers to deepen their knowledge of co-producing/engaging in participatory research with autistic individuals, and networking with potential co-producers from around Australia. Autism researchers attended the residential workshop for 1.5 days, with session topics and format for delivery as listed in Table 1.

4. Evaluation

4.1 Participants

Participants in the evaluation were autistic adults (n=13) and autism researchers (n=8).

4.2 Method

The method for evaluation were fit-for-purpose surveys, incorporating qualitative and quantitative questions.

4.3 Results

Overall ratings

Analysis of quantitative data, as shown in table 2, indicated high approval ratings for the modules (\bar{x} = 3.67), practical component (\bar{x} = 3.67), the residential workshop (\bar{x} = 3.88 for autistic participants, \bar{x} = 4.00 for autism researchers) and online sessions (\bar{x} = 1.17).

Table 2: Approval ratings for Program elements

Participant Stream		\bar{x} , mode (range)
Autistic participants	Overall rating of the modules (n=6)*	3.67, 4 (3-4)
Autistic participants	Overall online session efficacy (n=6)**	1.17, 1 (1-2)
Autistic participants	Overall rating of the practical component (n=3)*	3.67, 4 (3-4)
Autistic participants	Overall rating of the residential workshop (n=8)*	3.88, 4 (3-4)
Autism researchers	Overall rating of the residential workshop (n=4)*	4.00, 4 (4)

*scale: 1=poor, 2=okay, 3=good, 4=excellent

**scale: 1=useful, 2=not useful

Online modules and sessions

With regard to the **online modules**, the majority of participants completing the survey indicated they engaged in 'most or all' of the content and completed 'most or all' of the activities, as shown in table 3.

Table 3: Extent of engagement with online modules

Module topic	n, \bar{x} , mode (range)	
	Read content/activities or watched videos	Completed activities
Autism CRC and Inclusive Practice	6, 4.00, - (4)	6, 4.00, - (4)
Ethics	5, 4.00, - (4)	4, 4.00, - (4)
Participatory Research	6, 3.83, 4 (3-4)	6, 4.00, - (4)
Quantitative Research	6, 3.67, 4 (3-4)	6, 3.17, 4 (1-4)
Qualitative research	6, 3.67, 4 (3-4)	6, 3.17, 4 (1-4)
Mixed Methods Research	6, 3.50, 4 (3-4)	6, 3.17, 4 (1-4)
Research Dissemination	6, 3.33, 4 (1-4)	6, 2.83, 4 (1-4)

*scale: 1=none, 2=a little bit, 3=some, 4=most or all

Qualitative data responses indicated the modules as accessible and easy to understand. To highlight, two participants wrote:

I was impressed with the information. I've tried to learn about research methods and the research process etc before and never quite understood, but now feel like I have a solid grounding I can build on.

These modules were very educational and I am very grateful for them. They were presented in ways that were easy to understand. It was also really nice to be in an educational space that uses such accepting and thoughtful language.

With regard to the **online sessions** (n=7), the majority of participants completing the survey (n=6) attended an average of five sessions (\bar{x} = 5.33), watched one session recording (\bar{x} = 1.17), and indicated the online sessions as 'useful' – as shown in table 4.

Table 4: Engagement and usefulness of online sessions

	\bar{x} , mode (range)
Number of sessions attended (n=6)	5.33, 6 (2-7)
Number of session recordings watched (n=6)	1.17, 0 (0-5)
Usefulness of sessions* (n=6)	1.17, 1 (1-2)

*scale: 1=useful, 2=not useful

Qualitative data indicated the usefulness of the online sessions as being: allowing for questions to be asked; clarifying information; learning from others; and, meeting/connecting with others in the Program. As indicated by three participants:

Being able to ask questions, have information clarified, and hear others' questions and insights was really wonderful.

The online sessions were useful because I was able to listen to others with more experience in autism research talk about the content, and it gave context to it.

Being able to ask questions, have information clarified, and hear others' questions and insights was really wonderful. We would never have achieved that to the same level with simply pre-prepared training materials coming from fewer perspectives.

Practical component

All participants completing the survey (n=3) indicated the practical component as 'excellent' (n=2) or 'good' (n=1). One participant said:

I thought it was well done and enjoyed learning about a specific research study and having the chance to discuss it with the actual researchers.

Residential workshop

Quantitative data indicated high approval ratings for the workshop sessions, with the majority of participants in the autistic participant stream rating all the sessions as 'excellent', with the exception of a group presentation session. Participants in the autism researcher stream rated all sessions as 'good' (n=2) and 'excellent' (n=2), as shown in table 5.

Table 5: Residential workshop session ratings

Sessions	n, \bar{x} , mode (range)	
	Autistic participant stream	Autism researcher stream
Experiences of Research	8, 3.75, 4 (3-4)	-
Contributing to Co-Production/Participatory Research	8, 3.63, 4 (2-4)	-
Communication and Power Balance in Research	8, 3.75, 4 (3-4)	-
Participating in Research Opportunities	8, 3.63, 4 (3-4)	-
Q&A Panel with autistic leaders	8, 3.88, 4 (3-4)	-
Diamond Ranking Activity	8, 3.75, 4 (3-4)	4, 3.50, - (3-4)
Diamond Ranking Activity Presentations	8, 3.63, 3 (3-4)	4, 3.50, - (3-4)
Research Trends	6, 4.00, 4 (4)	4, 3.50, - (3-4)
Participatory Research/ Co-production	7, 4.00, 4 (4)	4, 3.50, - (3-4)

scale: 1=poor, 2=okay, 3=good, 4=excellent

Support practices

With regard to the **Preparation and Wellbeing Toolkit**, the majority of participants in the autistic participant stream completing the survey (n=9) indicated the toolkit as ‘useful’ (n=6), with the majority in the autism researcher stream completing the survey (n=4) indicating it as ‘somewhat useful’ (n=2), as shown in table 6. Qualitative data indicated it useful for participants to prepare and reflect on their needs in advance. One participant in the autistic participant stream said:

It was also reassuring to be able to communicate my needs this way, without feeling that I am making a big deal out of it, and knowing that my having such needs is understood and accepted.

A participant in the autism researcher stream stated:

I found the Toolkit to be incredibly thorough and useful for mentally and physically preparing for the workshop, understanding what my options would be on the day and overall reducing any anxiety about attending a new place with new people.

With regard to **support staff**, as shown on table 6, all participants in both streams who completed the survey (n=13) indicated having support staff available as 'beneficial' whether they utilised them or not. Qualitative data indicated benefits as including 'making everything easier', 'reassuring', and 'lessened anxiety'. A person from the autistic participant stream said:

It was really nice to have the support staff and I actually felt like they WANTED to make accommodations and help rather than just 'tolerating' requests like many people do.

A participant from the autism research stream stated:

It took a HUGE mental load off!! Not having to worry about "WHO" would I need to find/ask if I needed help, as well as knowing that I COULD actually ask for help without feeling embarrassed.

With regard the inclusion of a **therapy dog**, all participants from both streams completing the survey (n=13) indicated this as 'beneficial' whether they utilised him or not. Qualitative data indicated the benefits as including 'calming', 'enjoyable' and 'valuing adding', with one participant from the autistic participant stream stating:

Having a dog around gives people a connection that has no human expectations attached to it. You can look at, talk to and touch the dog and they have no expectation of you conforming to any social rules of conversation etc. The dog is also a great non-personal point of conversation that elicits positive feelings.

A participant from the autism researcher stream said:

It really helped to lighten the atmosphere and I think it was a very calming presence.

Table 6: Residential workshop support practices

	\bar{x} , mode (range)	
	Autistic participant stream n=9	Autism researcher stream n=4
Preparation and Wellbeing Toolkit Usefulness*	2.56, 3 (2-3)	2.00, 2 (1-3)
Support Staff Beneficial**	2.67, 3 (2-3)	2.75, 3 (2-3)
Therapy Dog Beneficial**	2.56, 3 (2-3)	2.50, - (2-3)

*scale: 1=no, 2=somewhat, 3=yes

**scale: 1=no, 2=yes, although I didn't need to utilise them, 3=yes

With regard to **inclusive and accessibility related practices**, autistic participant respondents were asked an open-ended question as to which inclusive and accessible practices they found most beneficial. These were indicated as:

- availability of sensory tools
- low lighting
- flexibility of attending sessions
- optional social activities
- flexible seating, including beanbags
- live-streaming of sessions so participants could watch from their room.

5. Conclusions

The evaluation data indicated highly successful and appropriate delivery in-line with the objectives of the Program. All Program elements were rated highly and identified through qualitative and quantitative data as delivered in an appropriate way.

Evaluation data and delivery team reflections indicated the added element of the practical component for the autistic participant stream, was appropriate to develop understandings of co-production in action. Also of note was the addition of the structured discussions and masterclasses for this stream. This was not intended as a core element of the Program, but was added to maintain momentum and engagement during the COVID-19 pandemic until such time as the residential workshop could be held. The topics chosen by the participants for these - such as autistic identity and masking, and self-care, sleep and sensory overload – indicates that engagement in the Program added value to participants beyond upskilling in co-production/participatory research. Reflections from the delivery team indicated this value as including community building and personal empowerment, and enabled participants to openly share and connect more deeply with others at the residential workshop.

Post-Program, participants continue to engage in research activities, both with Autism CRC as segue and independently. Activities have included engaging as research assistants and co-producers, being on advisory groups, presenting at the Australasian Society for Autism Research (ASfAR) conference (n=4) and upskilling international researchers in participatory research.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



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