



# Research Program 2020

## Executive Summary

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**Sylvia  
Rodger  
Academy**



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# Research Program 2020

## Executive Summary

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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 Charlotte Brownlow
- Dr Olivia Gatfield
- Gabby Hall
- Dr Jac den Houting
- Dr Wenn Lawson
- Prof Liz Pellicano
- Abby Sesterka.

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 Sylvia Rodger Academy, an initiative of Autism CRC, delivered the Research Program in 2015 and 2017 with the aim to upskill autistic adults and autism researchers in research co-production/participatory research. Based on feedback from participants and a project team comprising of autistic adults, researchers and alumni, the elements of the Program were expanded for delivery in 2020.

The elements of the Program for participants in the autistic stream of the Program: seven online modules and sessions; a practical component; online masterclasses and structured discussions; and, a 3.5-day residential workshop. For participants in the autism researcher stream, the elements included: reading/watching prescribed content and submitting written tasks; online masterclasses; and, attending the residential workshop for 1.5-days

This document provides a summary of the evaluation for the 2020 delivery. The full report can be viewed at [autismcrc.com.au](http://autismcrc.com.au).

## 2. Evaluation description

To evaluate the effectiveness and appropriateness of the elements of the Program, fit-for-purpose surveys were developed for Program participants in the two Program delivery streams, being autism researchers (n=8) and autistic adults (n=13).

## 3. Summary of findings

Analysis of the data indicated high approval ratings for the modules, online sessions, practical component, and the residential workshop.

**Online modules and sessions (n=7).** Participants in the autistic stream engaged in ‘most or all’ of the content and completed ‘most or all’ of the activities. The majority indicated the online sessions as ‘useful’, indicating the benefits as including: as being: allowing for questions to be asked; clarifying information; learning from others; and, meeting/connecting with others in the Program.

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**Practical component.** The majority of autistic stream participants completing the survey indicated this element as ‘excellent’ with espoused benefits as including enabling discussion of a specific co-produced research project with the actual researchers.

**Residential workshop.** The majority of sessions at the workshop were rated as ‘excellent’ by those in the autistic participant stream, with ratings of ‘good’ and ‘excellent’ by those in the autism research stream. With regard to the residential workshop support practices:

- **Preparation and Wellbeing Toolkit:** The majority of participants in the autistic participant stream completing the survey indicated the toolkit as ‘useful’, with the majority in the autism researcher stream completing the survey indicating it as ‘somewhat useful’.
- **Support staff,** all participants in both streams who completed the survey indicated having support staff available as ‘beneficial’, with qualitative data indicating benefits as including ‘making everything easier’, ‘reassuring’, and ‘lessened anxiety’.
- **Therapy dog.** All participants from both streams indicated this as ‘beneficial’ with qualitative data indicated the benefits as including ‘calming’, ‘enjoyable’ and ‘value adding’.
- **Inclusive and accessibility related practices.** The practices indicated as most beneficial were: availability of sensory tools; low lighting; flexibility of attending sessions; optional social activities; flexible seating; and, live-streaming of sessions so participants could watch from their room.

## 4. 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 apposite way.

With regard to the autistic participant stream, evaluation data and delivery team reflections indicated the added element of the practical component was appropriate to develop understandings of co-production in action. Further, that the added element of structured social discussions and masterclasses added value to participants beyond upskilling in co-production/ participatory research. Specifically, facilitating community building and personal empowerment, and enabling participants to openly share and connect more deeply with others at the residential workshop.

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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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