

Autistic Identity and Connection Program 2023: Evaluation report

Final Report

Kiah Latham, Hayley Clapham, Dr Olivia Gatfield, Ashton Bartz

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Kiah Latham

Autism CRC and Sylvia Rodger Academy alumni

Hayley Clapham

Autism CRC and Sylvia Rodger Academy alumni

Dr Olivia Gatfield

Autism CRC

Ashton Bartz

Autism CRC

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- Kathy Isaacs, Sylvia Rodger Academy alumni
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- Abby Sesterka.

Autism CRC

Autism CRC is 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.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

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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, 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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1. Background

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum, and has as its vision autistic people with quality of life and opportunity. The Sylvia Rodger Academy (SRA) is an initiative of Autism CRC, and supports this vision through providing programs, pathways and networks that create communities where autistic people fully contribute and influence policy, practice and culture in partnership with their peers.

Since 2015, SRA have delivered holistic empowerment programs to the autistic community is the areas of leadership, research, corporate governance and, co-design of self-advocacy employment resources. Through evaluation of our programs undertaken with the more than 100 graduates and the reflections of the autistic-majority project teams, it was identified that a central benefit of each program was a developing sense of autistic identity, and connection with other autistic people. To that end, the Autistic Identity and Connection Program was developed as the first SRA program to focus specifically on community connection and autistic identity.

In acknowledging the reduced access to services and community in low-socio economic areas, this Program was offered exclusively to autistic participants living in low socio-economic areas of three Australian States. Program participants were offered the opportunity to complete the Program in two streams - fully online or in an online and face-to-face environment. This document outlines the various elements of the 2023 delivery for the two streams, the support practices that were utilised and provides evaluation of the components.

2. Objectives

The objectives of the Autistic Identity and Connection Program were for participants to:

- develop an affirmative sense of identity as an autistic person through the program content and connections with other autistic people
- learn about the diversity of the autistic experience in the wider context of the autistic community
- enhance practical knowledge to build and reinforce skills for self-care and self-advocacy
- increase engagement with the autistic community, develop connections and network with other participants
- gain membership into the Sylvia Rodger Academy.

3. Participants and Program Elements

3.1 Participants

Forty-five autistic adults from New South Wales, Victoria, and Tasmania were selected to participate in the Program. Fifteen were enrolled in the online and face-to-face Program, and 30 in the online only Program. The elements of these are described sequentially below.

3.2 Program Elements

3.2.1 Online and face-to-face

The elements of the Program for this stream were:

1. Modules and online sessions

The purpose of this element was to enable participants to explore information about autism and common autistic adults' experiences – the goal being to increase knowledge and understanding of autism generally and in relation to self. Participants were provided with four modules, emailed or posted to each participant, prior to a corresponding online session. The modules covered the following topics:

- Autism
- The Autistic Experience
- Wellbeing
- Self-advocacy.

The modules included written content, videos, resources and additional readings. There was also an optional activity spanning the modules that facilitated participants to develop individual profiles and self-care toolkits.

The four online sessions were facilitated by the Project Officer and aimed to further knowledge of the module topic and facilitate peer-to-peer support and engagement. All sessions were recorded and made available to participants, for those unable to attend or wanting to review.

2. Residential Workshop

The purpose of the workshop, held in Melbourne over 3.5 days, was to provide opportunity for further connection, learning from established autistic leaders and exploration of concepts related to autistic identity. Participants engaged in two Q&A panels with autistic leaders as well as sessions on the topics of:

- Autistic identity
- Building connections to other autistic people, community, and autistic culture
- Ableism and internalised ableism
- Communication and the double empathy problem
- Masking and unmasking.

A number of support practices were implemented to facilitate participant engagement at the workshop, including having designated support staff, inclusive and accessibility practices, and a preparation and wellbeing toolkit. The toolkit 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 support plan to enable the Delivery Team to support people in their chosen way, if required.

3.2.2 Online only

The online only Program participants self-selected to join one of two groups. This enhanced peer-to-peer learning due to small group numbers, and provided opportunity for participants to engage in the online sessions by joining the group which best accommodated their schedules. The elements of the Program for this stream were:

1. Modules and online sessions

The purpose, content and methods were the same as for the online and face-to-face stream (see section 3.2.1).

2. Masterclasses

The purpose and topics of the masterclasses was that as for the residential workshop sessions for the online and face-to-face stream (see section 3.2.1). The five online masterclasses were hosted by established autistic leaders. All masterclasses were recorded for those who could not attend or wanted to review the session.

As with the online and face-to-face stream of the Program, participants were provided with a preparation and wellbeing toolkit. This version of the toolkit enabled participants to explore the components of the Program, create a plan to reduce concerns and prepare before the Program started.

4. Evaluation

4.1 Participants

Participants in the evaluation were autistic adults that completed the online and face-to-face stream (n=11) and the online only stream (n=21).

4.2 Method

Evaluation data was collected through quantitative and qualitative methods. With regard to the former, fit-for-purpose surveys were administered through Qualtrics at two time points- after module completion and at the end of the Program. The surveys included open end-questions and supplemented qualitative data which was collected through focus groups on completion of the Program. Development of the instruments, data collection, analysis and interpretation of data was undertaken by autistic individuals.

4.3 Data Analysis

Survey data was analysed using Excel. Focus group data was analysed using a "bottom up" approach whereby recordings of the focus groups were transcribed, and codes were assigned to each transcript. After assessing for similarity, codes were organised into preliminary themes. Further review revealed significant similarity between the themes for both participant streams (online and face-to-face, and online only) and as such the datasets were merged.

Intercoder reliability was achieved through a process of independent coding, followed by code verification and review from a second coder. Contentions were discussed until consensus was reached.

5. Results

5.1 Survey results

5.1.1 Program overall

To evaluate the impact of the Program, participants were asked to rate- before and after the Program- their level of isolation from other autistic people; skills and knowledge to improve their wellbeing; and knowledge about autistic experiences. As shown in table 1, the majority of participants (n=32) 'strongly agreed' that before the program they felt isolated from other autistic people (\bar{x} =2.06); 'agreed' they didn't have knowledge or skills to improve their wellbeing (\bar{x} =2.34); and, didn't have much knowledge about autistic experiences and identity (\bar{x} =2.47). After the program the majority of participants (n=30) 'agreed' they felt connected with other autistic people (\bar{x} =3.93); 'strongly agreed' or 'agreed' they had knowledge about autistic experiences and identity (\bar{x} =4.50); and, had skills or knowledge to improve their wellbeing (\bar{x} =4.23). Post-program, participants were also asked whether they felt more confident and comfortable because of the Program, with the majority having 'agreed' that they were more confident and comfortable because of the program (\bar{x} =4.03).

Table 1: Participant ratings for pre- and post-Program

Rating	Online & face-to-face n =11 \bar{x} , mode (range)	Online only n=21 (before) n=19 (after) \overline{x} , mode (range)	All n=32 (before) n=30 (after) \bar{x} , mode (range)
Before the Program, I felt isolated from other autistic people*	1.82, 1 (1-4)	2.10, 1,2 (1-4)	2.06, 1 (1-4)
After the Program, I feel connected with other autistic people**	4.45, 5 (3-5)	3.63, 4 (2-5)	3.93, 4 (2-5)
Before the Program, I didn't have the skills or knowledge to improve my wellbeing*	2.09, 2 (1-4)	2.48, 2 (1-4)	2.34, 2 (1-4)
After the Program, I have skills or knowledge to improve my wellbeing**	4.45, 5 (3-5)	4.11, 4 (3-5)	4.23, 4 (3-5)
Before the Program, I didn't have much knowledge about autistic experiences and identity*	1.82, 2 (1-4)	2.81, 2,4 (1-5)	2.47, 2 (1-5)
After the Program, I have knowledge about autistic experiences and identity**	4.64, 5 (4-5)	4.42, 4 (4-5)	4.50, 4,5 (4-5)
I am more confident and comfortable because of the program**	4.27, 5 (3-5)	3.89, 4 (3-5)	4.03, 4 (3-5)

^{*}Scale: 1=Strongly Agree, 2=Agree, 3=Unsure, 4= Disagree, 5= Strongly Disagree

^{**}Scale: 1=Strongly Disagree, 2=Disagree, 3=Unsure, 4= Agree, 5= Strongly Agree

5.1.2 Online modules and sessions

Analysis of quantitative data, as shown in table 2, indicated high approval ratings for the online modules overall (\bar{x} = 3.53) and online sessions overall (\bar{x} = 3.16) with the majority of participants from both streams rating the modules and online sessions as 'good' or 'excellent'.

Table 2: Ratings for online modules and sessions

Activity	$ar{x}$, mode (range)	
Overall rating of online modules*	3.53, 4 (2-4)	
Online and face-to-face group* n= 11	3.64, 4 (2-4)	
Online only group* n= 21	3.48, 4 (2-4)	
Overall rating of online sessions*	3.16, 4 (2-4)	
Online and face-to-face group* n= 11	3.27, 3 (2-4)	
Online only group* n= 21	3.14, 4 (2-4)	

^{*}Scale: 1=poor, 2=okay, 3=good, 4=excellent

As shown in table 3, the majority of participants across both streams indicated they had read some or all of the module content and attended an average of three online sessions. Of interest, 28% of participants watched at least one recording of a session that they had also attended.

Table 3: Engagement with online modules and sessions

Engagement activity	Module 1: Autism \overline{x} , mode (range)	Module 2: The Autistic Experience \overline{x} , mode (range)	Module 3: Wellbeing \overline{x} , mode (range)	Module 4: Self-Advocacy \overline{x} , mode (range)
Read some or all of the module**	1.03, 1 (1)	1.00, 1 (1)	1.03, 1 (1-2)	1.03, 1 (1-2)
Online and face-to-face group** n= 11	1.09, 1 (1-2)	1.00, 1 (1)	1.00, 1 (1)	1.00, 1 (1)
Online only group** n= 21	1.00, 1 (1)	1.00, 1 (1)	1.05, 1 (1-2)	1.05, 1 (1-2)
Attended online session**	1.19, 1 (1-2)	1.19, 1 (1-2)	1.41, 1 (1-2)	1.31, 1 (1-2)
Online and face-to-face group** n= 11	1.09, 1 (1-2)	1.27, 1 (1-2)	1.27, 1 (1-2)	1.18, 1 (1-2)
Online only group** n= 21	1.24, 1 (1-2)	1.14, 1 (1-2)	1.48, 1 (1-2)	1.38, 1 (1-2)
Watched online session recording**	1.66, 2 (1-2)	1.69, 2 (1-2)	1.56, 2 (1-2)	1.66, 2 (1-2)
Online and face-to-face group** n= 11	1.82, 2 (1-2)	1.64, 2 (1-2)	1.55, 2 (1-2)	1.64, 2 (1-2)
Online only group*) n= 21	1.57, 2 (1-2)	1.71, 2 (1-2)	1.57, 2 (1-2)	1.67, 2 (1-2)

^{*}Scale: 1=yes, 2=no

Open ended questions in the survey regarding the **online modules** indicated these as beneficial. Specifically, facilitating an increase in knowledge of autism and understanding of self, and a foundation for self-care, advocacy and life skills. Three participants said:

This knowledge is helping me process and put into order a lot of information that just didn't quite make sense before (online only participant).

They have given me tips on how to manage myself (emotionally) and my sense of identity. They have also helped me feel connected to others, as I read about similar experiences. I think it was good that the modules weren't about conforming to society, but advocating for self - even if you are "different" from others (online and face-to-face participant).

I have understood better, how to help others understand me with my Autistic profile. It wasn't until after the second module that I realised how helpful the Autistic profile was for myself and others around me. The Wellbeing module was fantastic (online only participant).

With regard to the **online sessions** it was indicated that these were beneficial to connect with other autistic adults. Participants said the online sessions were a safe place that allowed them to hear others' experiences and to share their own experiences.

The online sessions are the first time I have officially been with other people that I know are also on the spectrum. It is also the first time in a long time that I have felt like attending anything with other people. The reason this is important is that it makes you feel safe enough, particularly online, to attend and interact at a level where anxiety is decreased because there is trust there (online only participant).

The online sessions have been invaluable. Having only been diagnosed only 4 years ago and not knowing anyone with Autism it has been great to hear other people's responses and thoughts on each of the topics. I feel less alone in my journey towards better understanding Autism and how it affects me in my everyday life (online and face-to-face participant).

Participants noted that the sessions being held online increased their capacity to; focus, participate and use preferred communication styles. The recordings of the sessions allowed for increased access and ability to process information. One participant said:

Online is helpful for my busy schedule and also for the harder days where i feel like hiding but also don't want to miss out. I liked having different communication options offered. [...] The recordings are also sooo helpful for re-watching and the chat box is helpful for the impulse blurting (online only participant).

5.1.3 Residential workshop

Quantitative data indicated a high level of approval for the residential workshop - all the participants who completed the survey (n=10) rated the residential workshop overall as 'excellent' (\bar{x} =3.90), with the exception of one 'good'. The data also indicated a high level of approval for each of the workshop sessions individually with the majority of participants rating each workshop session as 'good' or 'excellent', as shown in table 5.

Table 5: Residential workshop session ratings

Sessions	$ar{x}$, mode (range) n=10
Residential workshop overall	3.90, 4 (3-4)
Autistic Identity	3.30, 3 (3-4)
Building connections to other autistic people, community, and autistic culture	3.10, 3,4 (1-4)
Communication and the double empathy problem	3.50, 4 (2-4)
Q&A panel with autistic leaders 1 (day 2)	3.30, 3 (2-4)
Ableism and internalised ableism	3.10, 4 (2-4)
Masking and unmasking	3.70, 4 (2-4)
Q&A panel with autistic leaders 2 (day 3)	3.30, 3 (2-4)
Addressing the Parking Lot	3.40, 3 (3-4)
Leaving Autistic Space	3.30, 3 (3-4)
Evaluation session focus group	3.20, 4 (2-4)

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

Open ended survey questions regarding the **residential workshop** indicated the participants found this beneficial to: making connections with other autistic people and experiencing autistic space; increased understanding of self, and; improved self-image and self-acceptance through building a positive autistic identity. Two participants said:

I am more aware of myself and my needs. I have learnt many accommodations I can make in my life to make things easier on myself. Mostly I learnt it's OK to be autistic and I am moving into a space where I want to be autistic and proud and educate others on autism.

The residential workshop has changed my life and opened me up to a new level of self insight I didn't have access to before. Meeting and getting to speak to people who share so many similar experiences to me was validating and illuminating. It really helped me move from a space of "imposter syndrome" and "internalised ableism" to a somewhere more self-accepting and pragmatic. I have already made big changes in my day to day life to honor unique autistic needs which I may never have done without this workshop. I also feel more empowered socially to try and make new connections suited to my communication and relationship needs. All of these things have really improved my capacity to live an authentic and fulfilling life and contribute to the community.

5.1.4 Online masterclasses

Quantitative data indicated high approval ratings for the online masterclasses with the majority of participants (n=19) rating the online masterclasses overall as 'excellent' (\bar{x} = 3.63). Each of the masterclass sessions were rated as 'excellent' by the majority of participants who attended the session or watched the recording, as shown in table 4.

Table 4: Online masterclass sessions ratings

Sessions	n, $ar{x}$, mode (range)
Online Masterclasses overall	19, 3.63, 4 (2-4)
Autistic Identity	14, 3.64, 4 (3-4)
Building connections to other autistic people, community, and autistic culture	13, 3.62, 4 (2-4)
Communication and the double empathy problem	13, 3.69, 4 (3-4)
Ableism and internalised ableism	14, 3.50, 4 (1-4)
Masking and unmasking	15, 3.60, 4 (2-4)

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

Open ended survey questions indicated the benefit of the online masterclasses as: providing information and examples on navigating life as an autistic individual; validation of the autistic experience, and; allowing self-reflection and building self-confidence. Responses further indicated that participants valued these being presented by knowledgeable autistic people who could speak of their experiences. Three participants said:

Info and support from autistics regarding navigating life as an adult autistic. Validation that being autistic is a continuous journey of self discovery and fluctuating needs.

I am more relaxed with the idea of having an Autistic Identity.

Good to observe other women and how they are experiencing life as autistic in positive ways. This gives me hope I can live true to myself and it is still ok to be me.

5.1.5 Support practices

With regard to the **preparation and wellbeing toolkit**, the majority of participants completing the survey (from both streams of the Program) read or filled out 'all' of the toolkit (\bar{x} =2.69) and found it to be useful (\bar{x} =2.64) as shown in table 6.

Table 6: Program support practices

Survey	$ar{x}$, mode (range)	
Read/ filled out the Preparation and Wellbeing Toolkit* (n=29)	2.69, 3 (1-3)	
Preparation and Wellbeing Toolkit Usefulness** (n=28)	2.64, 3 (1-3)	
Support Staff Beneficial*** (n=10)	2.60, 3 (2-3)	

^{*}Scale: 1=no, 2=Yes, some, 3=yes, all

Open ended questions indicated it was useful in preparation for the Program and self-reflection. As indicated:

It was a good exercise to get me thinking about my needs and what help I need during times of stress and anxiety.

It was good that I was able to write down any thoughts/feelings/concerns into each section and figure out what my best approach was/is for each scenario. I also appreciate all the examples for each question, so I knew with more certainty what each section was asking of me.

With regard to **support staff** at the residential workshop, all participants completed the survey (n=10) indicated that this was beneficial (\bar{x} =2.60), even if they did not need to utilise them, as shown in table 6. Open ended questions indicated the benefit of support staff as a 'decrease in anxiety' knowing they were available when needed. One participant said:

The workshop was such an unexpectedly emotionally intense and mentally draining experience. I didn't think I would need to utilitise the support staff but found myself making contact multiple times for various practical issues. It also improved my ability to engage more deeply with the experience as we were scaffolded by the built in support e.g. being met at the airport, and staff proactively offering support when I couldn't ask for it - I didn't have to worry as much as I usually did about logistics, which helped me relax and be more present.

With regard to **inclusive and accessibility related practices** at the residential workshop participants found most beneficial, these were indicated as:

- a quiet space
- low lighting
- social activities being optional
- flexibility of attending sessions in person or via live-streaming from their room
- availability of sensory tools
- information about the venue given in advance
- time given to allow 'recovery' between sessions.

^{**}Scale: 1=no, 2= somewhat, 3=yes

^{***}Scale: 1=no, 2=yes, although I didn't need to utilise them, 3=yes

5.2 Focus Group Results

Analysis of the data revealed three themes shared across both streams, these are presented below with example quotes from participants.

5.2.1 Theme 1: "...not something I've ever had" – included, accepted and connected with community for the first time

This theme indicated the Program was an opportunity for participants to connect with other autistic adults, many for the first time. The participants spoke about gaining a sense of belonging to a community, feeling welcome and included. As participants said:

there's just been a really good space to like be around other autistic people. Cause it's like obviously not something I've ever had (online and face-to-face participant).

I've enjoyed the inclusion. I've really enjoyed feeling part of something (online only participant).

It really increased me sense of belonging to the community (online only participant).

One participant expressed that being in autistic space allowed them to speak openly about topics that they hadn't previously felt comfortable discussing in other settings, they said:

Its great how we can be vulnerable here.... talk about you know stuff like. Cause normally those stuff you feel uncomfortable talking outside (online and face-to-face participant).

5.2.2 Theme 2: "helped me feel more confident in a lot of things" - more confident, self-accepting and can advocate for self and others

This theme encompassed participant discussion that the Program helped them build confidence, become more self-accepting and develop advocacy skills. Two participants said:

I like how all of this kind of resonates in us. And because of that, it kind of makes you feel confident (online and face-to-face participant).

so it's been nice to, yeah feel like it's ok to say yes, I am autistic (online only participant).

The participants noted that this was not only beneficial to them individually and spoke about using the knowledge and skills gained from the program to benefit others in the autistic community. As two participants said:

And as well as noticing how I can advocate for myself but passing on those skills to the other students while they're still young, is something that like I feel I missed out on, but now being able to say, hey, I can do this... So, sort of being an advocate for them (online and face-to-face participant).

I have much more ambition to reach out to other people and I've only just started since I joined this course, like, trying to make my own little community of people. So just through the course as well, I've been able to help other people feel the safety and have the space to be themselves too, which is so beautiful (online and face-to-face participant)..

5.2.3 Theme 3: "I am not alone"- validating identity and experience

This theme illustrated that participants gained validation of their own autistic identity by hearing others and sharing their experiences with other autistic individuals. Three participants said:

You think to yourself, oh, it's not just me who does those sort of things.... I'm discovering by listening, that it is part of my autistic personality (online only participant).

I think my favourite part was hearing other people's experiences.... and I think that had a big impact, like hearing it in context and then being able to relate and feeling like, you're not alone (online and face-to-face participant).

.. I'd be like, well, that's because my mental health issues, you know, that's me being crazy. Other people don't feel like this, but now I realise that it's not that I was crazy, it's just I'm autistic and I don't understand the world the way it's currently functioning (online only participant).

Participants also discussed gaining insight to the diversity of the autistic experience as they were exposed to experiences that also differed to their own. As one participant said:

I liked hearing about other people's experiences, even if they are quite different to my own. Being able to hear from and learn from other autistic people is good, especially as I don't really see other autistic people in everyday life (online only participant).

6. Conclusions and Recommendations

Evaluation data indicated highly successful and appropriate delivery of the Program in line with the objectives. Central to this success, however, was development, delivery and evaluation of the Program by an autistic project officer and majority autistic delivery team. This enabled the content and teaching to be grounded in autistic perspectives.

Feedback gathered from participants outlined areas of the Program with potential for development and improvement. This included:

- additional workbook activities to do in own time, providing structure to explore and understand the content more fully
- additional supports to aid participants to learn and engage in the content and program, including visuals and audio recordings
- more topic focused prompt questions, given in advance, for online sessions; and preparation activities for masterclasses
- additional content including: the history and evolution of language use and preferences;
 "coming to terms with" being recently diagnosed and late diagnosis; masking/ camouflaging in navigating life tasks
- more diverse representation and experiences (including non-speaking).

While both streams commented positively on the inclusive practices utilised, there was higher attrition for program participants in the online only stream. Some participants in this stream said they struggled to attend sessions regularly due to scheduling, and other participants indicated that the Program could be improved by providing additional ways for people to contribute to sessions. Accordingly, it is recommended that a modified delivery method be considered which enables participants to contribute to discussions in an online environment and explore content with self-paced progression.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



Independent national source of evidence for best practice







