Sylvia Rodger Academy

Co-design with the autistic community: Self-Advocacy@Work

Evaluation Report

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AutismCRC

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Acknowledgements

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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 Commonwealth 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, 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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1.   Background

The co-design of research, products and services is fast becoming the gold standard, with many funding bodies, including Government, requiring co-design for grants and initiatives, such as the development of the National Autism Strategy. However, there is a lack of understanding of how the co-design processes can be adapted to be respectful and responsive to the autistic community.

The aim of the Self-Advocacy@Work project was to develop and disseminate employment self-advocacy resources by, and for, the autistic community utilising co-design methodologies. This report provides evaluation of the processes by which the autistic community were engaged in the co-design processes.

1.1   Co-design

Co-design is an **investigative and creative process** that brings together people who are impacted by the product, service, or resource (also known as an 'output') and people with knowledge and technical skills to jointly create something. Co-design aims to empower and put people with lived experience at the centre of the design process, recognising that with lived experience are the people who know best.

The purpose of co-design is to bring unique perspectives and expertise together to jointly create a solution, product, or service. The benefits of co-design include to:

- empower people to recognise that they are experts of their own experience
- help to solve real life problems
- aid in understanding unique perspectives
- provide opportunities for community input
- generate and test ideas, and
- provide valuable insight on whether something is likely to work in the real world.

There is no single standard framework or process for co-design. The co-design process adopted for the Self-Advocacy@Work project is shown in figure 1.

Figure 1: The co-design process used for the Self-Advocacy@Work project

Research → Define → Ideate → Prototype → Test → Deliver

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1.2   Participants and the Sylvia Rodger Academy

An initiative of Autism CRC, the Sylvia Rodger Academy (SRA) delivers holistic nationwide programs aimed at empowering autistic adults. SRA have been delivering programs since 2015 in the areas of leadership; corporate governance; research; and, autistic identity and connection. At the time or writing, over 150 people were graduates of, or currently engaged, in SRA Programs.

Given the lack of understanding as to how to tailor the co-design process effectively and appropriately to the autistic community, graduates of SRA were recruited to participate in the co-design as a working group. This leveraged established and trusting relationships which was deemed necessary to facilitate power sharing (den Houting, 2021) and safety during engagement in the co-design process. The latter being of significance given the project anchor of 'work', and poor employment outcomes for, and experiences of, autistic Australians (see Commonwealth of Australia, 2022).

1.3   Project objectives

The aim of the project was the co-design, development and dissemination of employment self-advocacy resources by, and for, the autistic community. The objectives to which this evaluation report relates, were to:

a. upskill members of the autistic community in co-design, product development and inclusive practices
b. develop an inclusive co-design process to ensure effective and appropriate engagement for autistic individuals, and
c. engage with the autistic community in the co-design process.

1.4   Project elements

To meet the objectives, the project elements were:

- **Four modules.** The purpose of the modules was to upskill the working group in the theory related to co-design and processes, and ensure a consistent level of conceptual understanding across the working group and team prior to the residential workshop. The first module was an introduction to co-design with subsequent modules covering stages of the co-design process. Specifically, 'research and define', 'ideate and prototype' and 'test and deliver'. The modules were developed by Autism CRC's Digital Product Manager, using accessibility principles developed by SRA.
- **Five online sessions.** The purpose of the online sessions were to: further upskill working group members in co-design; provide opportunity to ask questions and clarify module content; and, meet each other prior to the residential workshop. The online sessions complemented the modules by developing working group members understanding of co-design through addressing the theory-practice gap. For each session, a practical problem was consistently used to apply theory to practice, and pre-reading of each module prior was encouraged. Sessions were recorded and distributed for those who could not attend or wanted to process the information further.

- A **3.5 day residential workshop** held in Brisbane with the working group members, project and delivery team. The purpose of the workshop was to authentically engage the working group in an inclusive co-design process. The co-design process was focused on 'Self-Advocacy@Work', and utilised the following **activities and processes**:
  - stakeholder mapping
  - collaboratively defining "Self-Advocacy @ Work"
  - creating an initial (high level) research statement
  - identify stakeholders
  - journey mapping
  - ideation, including desirability, feasibility and success measures
  - elevator pitches
  - wireframing activities
  - LEAN canvas construction
  - identification of aspects and assumptions to consider in testing concepts.
  - The **inclusive and accessibility related practices** utilised at the workshop were that consistent with the Guidelines for Creating Autistic Inclusive Environments (Gatfield, Hall, Isaacs & Mahony, 2018). These included:
    - availability of sensory tools
    - low lighting
    - flexibility of attending sessions
    - optional social activities
    - flexible seating, providing opportunity for people to lie down
    - designated regular breaks
    - encouraging multi-tasking for those who utilise this for focus e.g. crafting while listening
    - colour coded communication 'dots' to indicate desired level of communication
    - live-streaming of sessions so participants could watch from their room
    - having designated support staff.

To support working group members wellbeing throughout the program, and subsequently their engagement with the project elements, a **Preparation and Wellbeing Toolkit** was developed with a registered psychologist. This enabled working group members to familiarise themselves with project elements and: plan for how to prepare themselves; reduce concerns and build resilience; and, develop a crisis plan to be used by themselves and/or the workshop delivery team.

2.   Evaluation

2.1   Participants

The participants for evaluation were autistic adults who were members of the working group (n=10). The participants were aged over 18 years, and from across Australia.

2.2   Method

Participants completed two fit-for-purpose surveys, administered through Qualtrics.

2.3   Results

This section provides evaluation data, with evaluation of the elements provided sequentially.

2.3.1   Modules and online sessions

With regard to the modules, the majority of participants completing the survey (n=8) rated the online modules as 'excellent' (n=5, $\overline{x}$=3.63), and read 'all' of each module ($\overline{x}$=3.75 to 4.00), as shown in Table 1.

Table 1: Rating of, and engagement with modules

Rating	$\overline{x}$, mode (range) n=8
Overall rating of modules*	3.63, 4 (3-4)
Overall rating of online sessions*	3.75, 4 (3-4)
Module 1: Introduction to co-design**	4.00, 4 (3-4)
Module 2: Co-design stages- research and define**	3.75, 4 (3-4)
Module 3: Co-design stages- ideate and prototype**	3.75, 4 (3-4)
Module 4: Co-design stages- test and deliver**	3.88, 4 (3-4)

*scale: 1=poor, 2=okay, 3=good, 4=excellent
** scale: 1=none, 2=some, 3=most, 4=all

Qualitative question responses highlighted the usefulness of the modules to "frame" the theory. It was noted by a number of participants that the pace, progression, format, layout was conducive to learning. As stated by two participants:

> **I liked the way that the modules used examples of things I could personally relate to. I wouldn't change anything in the modules.**

> **As a dyslexic person I found everything easy to read and the pictures were also hugely helpful. A lot of the information was new to me, but it wasn't overwhelming.**

One participant indicated that the modules could be improved by the inclusion of questions and activities.

With regard to the online sessions, the majority of participants completing the survey (n=8) rated the online sessions as 'excellent' (n=6, $\bar{x}$=3.75), as shown in Table 2.

Table 2: Rating of, and engagement with modules

Rating	$\bar{x}$, mode (range) n=8
Overall rating of online sessions*	3.75, 4 (3-4)

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

Qualitative question responses highlighted the benefit of the online sessions as including: to "solidify", "crystallise", "consolidate" and "clarify" module content; meet other members of the group and learn from them; and, build relationships with the working group and team. A number of participants also identified the utilisation of inclusive practices as beneficial to engagement, for example the option to have their cameras off and equally valuing typed and verbal input. As stated by two participants:

> **It felt like a safe place to contribute to the discussion and respectful of all viewpoints.**

> **I found the sessions very useful. It helped me to hear Brendan (the facilitator) break down everything we were learning in the modules. Everything was relatable and the language was at my learning level. I also enjoyed learning from the other participants.**

2.3.2   Residential Workshop

As shown in Table 3 below, the majority of participants completing the survey (n=9) rated the residential workshop as 'excellent' (n=7, $\bar{x}$=3.78). Open ended question responses spoke to the value of: having support staff; the supportive practices and process used; and, providing programs such as this. As stated:

> **The support team was great they knew what kind of support I needed throughout and were willing to change the level of support which I thought was fantastic because I needed different levels of support depending on my needs change.**

> **Very inclusive atmosphere and encouraging.**

> **It was such a welcoming and affirming experience the whole way through.**

> **Without the CRC and its programmes soo many of us would not be smashing the goals that we are in the community.**

> **Everything we did extended my knowledge and skills.**

> **This was such a unique experience... to be myself... I'd not experienced this in a professional setting before... being a mostly non-verbal participant. I cannot express how much this has meant to me, and how much it has given to me that I can give to others in return.**

Table 3: Rating of residential workshop overall and activities

Rating	$\bar{x}$, mode (range)
Residential workshop overall (n=9)	3.78, 4 (3-4)
Stakeholder mapping activity (n=10)	3.80, 4 (3-4)
Journey map activity (n=10)	3.60, 4 (2-4)
Ideation activity (n=10)	3.80, 4 (3-4)
Elevator pitches activity (n=10)	3.50, 4 (1-4)
Wireframing activity (n=10)	3.50, 4 (1-4)
LEAN Canvas activity (n=10)	3.60, 4 (2-4)

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

With regard to the activities, the most common rating was 'excellent' (mode=4, $\bar{x}$=3.50 to 3.80), as shown on Table 3 above. Open ended question responses indicated that the activities enabled participants to aptly engage in the processes through the provision of "structure" and "scaffolding". As stated:

> **... having the scaffolded structure really helped me be successful in completing this task. Just being told you need to write an elevator pitch 'go for gold', I would not be able to do as I need concrete boundaries to guide the process.**

> **It was scaffolded well for us to be able to complete it. Using the templates that were created definitely helped have clarity around what we needed to do.**

It was also indicated that having visual representation of ideas generated through activities, and utilising large group work, small group work, and presentations, was facilitative of participant engagement. With regard to visual representation it was commented:

> **Loved the printed out posters that were stuck on the walls keeping track of suggestions made and progress of ideas.**

> **It helped us see the overall picture.**

With regard to utilising small and large group work and presentations it was stated:

> I really liked the mixture because I learn best through experimental, kinaesthetic (sensory), and practical learning.

> It meant that it was not only informative/educational, but also interactive. It also meant that for those of us, who found it at times difficult to participate in large group work, they were still able to participate in the small group work.

> The combination was fantastic. It helped me communicate with group members I didn't know and it helped me create space for my peers to share their ideas.

2.3.3 Preparation and Wellbeing Toolkit

All participants (n=10) read 'some' or 'all' of the toolkit (mode=3, $\bar{x}$=2.80), with the majority completing 'all' of the toolkit ($\bar{x}$=2.30, mode=3) and indicating it as useful ($\bar{x}$=2.63, mode=3), as shown on Table 4.

Table 4: Engagement with Preparation and Wellbeing Toolkit

Rating	$\bar{x}$, mode (range)
Read the toolkit* (n=10)	2.80, 3 (2-3)
Level of completion* (n=10)	2.30, 3 (1-3)
Usefulness** (n=8)	2.63, 3 (2-3)

*scale: 1=none, 2=some, 3=all
**scale: 1=no, 2=somewhat, 3=yes

As stated by one participant:

> The toolkit process provided reassurance that I was prepared for the workshop and that I knew how to manage any situation (and who to speak to) that may come up.

3.   Conclusions

The objectives of the project, to which this evaluation report relates, were to: upskill members of the autistic community in product development and inclusive practices; develop an inclusive co-design process to ensure effective and appropriate engagement for autistic individuals; and, engage with the autistic community in the co-design process. The evaluation data indicated that the project was successfully delivered in line with these objectives.

Typically, the co-design of research, products and services is fast-paced, with engagement through the process being as little as six hours. Often, the stages of the co-design process and the aim of co-design – to empower and put people with lived experience the centre of the design process – is compromised.

This project has demonstrated that fidelity to the co-design process, without compromise, can be attained in a way that benefits the end-user community not just through the delivery of the co-designed research, product or service, but through an empowering experience. This empowerment should not just be considered in terms of 'effective and appropriate and engagement' as per the objectives of this particular project, but empowering community members to more fully understand, lead and advocate for authentic co-design.

4.   References

Commonwealth of Australia (2022). Services, Support and Life Outcomes for Autistic Australians. Canberra: Commonwealth of Australia.

den Houting, J. (2021). Participatory and Inclusive Autism Research Practice Guides. Brisbane: Autism CRC.

Gatfield, O., Hall, G., Isaacs, K. & Mahony, J. (2018). Guidelines for Creating Autistic Inclusive Environments. Brisbane: Cooperative Research Centre for Living with Autism.

Our values

Inclusion
Valuing lived experience

Innovation
Solutions for long term challenges

Evidence
Truth in practice

Independence
Integrity through autonomy

Cooperation
Capturing opportunities together

AutismCRC

Independent national source of evidence for best practice