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Centre for Program Evaluation & Melbourne Disability Institute

[Identifier-second line]

Evaluation of the Autism Peer Assist Pilot Project

Prepared for Amaze by the Centre for Program Evaluation

22 August 2022

ACKNOW Thanks Anthea. At this stage I’ll provide you my feedback by email because honestly I’m fully booked with meetings and commitments for the next 10 days.

In regard to this project it has been an interesting journey on one hand with providing self advocacy skills development and human rights awareness during a pandemic and lockdown for two years, in a time where participants were looking forward to stay connected online but not everyone was actually able to achieve it.

Main barriers to online connection were lack of equipment and knowledge on how to use this technology.

On the other hand, we struggle a lot to start support groups in regional areas and some metro areas because we didn’t have connections with the local communities and service providers in those areas.

Participants who attended the groups were very pleased of their involvement and learning but everyone lamented that more time is needed to develop the confidence to speak up and develop skills to know and apply their rights in an everyday setting.

There’s no doubt that my suggestion for the future is that a project of this magnitude does require more funding, resources and time to be carefully implemented for the long term benefit of the participants. Funding needs to have a timeframe of 3 to 5 years instead of the current 18 months. Funding timeframe should be linked to the goals of the project rather than bureaucracy.

If you require any further clarification or have any questions please let me know.

Regards,

Christian Astourian

LEDGEMENT OF TRADITIONAL OWNERS

The University of Melbourne acknowledges the Aboriginal and Torres Strait Islander traditional owners of the unceded land on which we work and learn. We pay respect to the Elders, past and present, and the plac ACKNOWLEDGEMENT OF TRADITIONAL OWNERS

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Acknowledgments

The Melbourne Disability Institute and the Centre for Program Evaluation at The University of Melbourne would like to acknowledge the assistance given to the researchers in this evaluation by the staff and the participants associated with Amaze.

We also thank the members of the CPE team for your support and contribution during the evaluation.

The Centre for Program Evaluation

Lauren Piko

Oskar Weimar

Wan Yi Lee

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| --- | --- | --- |
| Version Number | Status  | Date Submitted |
| Version 1 | Draft | July 2022 |
| Version 2 | Final Report | August 2022 |

# Context

**Recommended citation**

Rutter, A., Garcia-Melgar, A., & Lee, W. Y. (2022). Evaluation of the Autism Peer Assist Pilot Project: *Prepared for Amaze* by the Centre for Program Evaluation & Melbourne Disability Institute, The University of Melbourne.

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**The University of Melbourne**

The University of Melbourne has over 160-years of history of leadership in research, innovation, teaching and learning. It is the highest-ranked research university in Australia. Our researchers are at the forefront of international scholarship in a diverse range of fields.

**Melbourne Disability Institute**

The Melbourne Disability Institute (MDI) is an interdisciplinary research institute that was established by the University of Melbourne in 2018 to build a collaborative, interdisciplinary and translational research program to improve the lives of people with disability. Ultimately, the MDI research program aims to capitalise on national reforms and active partnerships with the disability sector to deliver evidence for transformation. The MDI research program is centred around providing much-needed evidence for the disability sector and broader community to address the complex problems facing people with disability, their families and carers.

**Centre for Program Evaluation**

The Centre for Program Evaluation (CPE) undertakes evaluations and research projects for government departments, non-government organisations and community-based agencies across a wide range of policy and program areas but particularly in the areas of education, health, the arts, social wellbeing and the community. Staff members are skilled in the use of widely known, as well as current, emerging and innovative evaluation theory, techniques, and practice, all of which aim to enhance client and stakeholder collaboration and increase the utilisation of evaluation findings.

**Community Based Research Scheme**

This project was conducted and funded through the Melbourne Disability Institute Community-Based Research scheme. The scheme is designed to build the evidence in the disability sector, by linking community organisations to researchers at The University of Melbourne. Projects funded through the scheme include small-medium projects suggested by community-based organisations that build social capital and improve lives of people with disability, their families or carers. The community-based research scheme is intended to support research and evaluation of innovative ideas that build social capital; to share good practice; and to replicate or scale up ideas.

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List of Abbreviations

|  |  |
| --- | --- |
| Abbreviation | Full text |
| COVID-19 | Coronavirus Disease 2019 |
| CPE | Centre for Program Evaluation |
| LGBTIQA+ | Lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual |
| MDI | Melbourne Disability Institute |
| NDIS | National Disability Insurance Scheme |

# Plain Language Summary

**The Evaluation**

Amaze was a successful recipient of the MDI Community Based Research Program Grants, and were partnered with the Centre for Program Evaluation (CPE) to evaluate the Autism Peer Assist (APA) pilot project. The aim of the APA project is to support families and carers of autistic children by putting them in contact with other carers who have similar life experiences (peer mentors). We evaluated how well the project was running, whether carers thought it was helpful, and if there are aspects of the project that Amaze can improve. This evaluation was funded by a Community Based Research Scheme through the Melbourne Disability Institute. The aim of the Community Based Research Scheme is to help community organisations conduct research or evaluation of programs that are making a difference in the lives of people with disability and their families/carers.

**What we did**

To evaluate the project, we talked to carers and their peer mentors, and also asked them to complete questionnaires about the project. They told us about:

* If they thought participating in the project helped them.
* What they learned during the project.
* What worked well.
* What things could be improved.

**What we found**

Carers felt supported

The carers who participated in this project told us that they felt supported by the peer mentors. They said they learned new strategies to help their children and felt more confident. They also learned more about services for autistic children.

The peer mentors showed empathy and understanding

The project was successful because the peer mentors had similar experiences and understood what the carers were going through. The peer mentors helped the carers feel less isolated.

**Recommendations**

There are a few things that Amaze can do so the APA project continues to be successful:

* Give carers and peer mentors more flexibility to decide how many times they meet.
* Ask peer mentors and carers to discuss how they want to run the sessions.
* Make the software and questionnaires for carers easier to understand and use.
* Keep recruiting peer mentors who understand carers’ experiences.

# Report Structure

This report presents the findings and recommendations of the evaluation of the “Autism Peer Assist Pilot Project” conducted by the Centre for Program Evaluation (CPE). The document is structured as follows:

**Section 1 Introduction** provides a background to the project, the purpose of the evaluation and the key evaluation questions.

**Section 2 Methodology** presents the rationale and design of the evaluation, the sampling, data collection, and analytical methods.

**Section 3 Results and Discussion provides a discussion of** key findings in relation to the evaluation questions.

**Section 4 Conclusion** is an overview of key findings.

**Section 5 Recommendations** provides an overview of recommendations based on the analysis and discussion of key findings, and discussion with Amaze.

1. Introduction

The funding for the Autism Peer Assist Pilot project was provided by a charitable foundation with matched funding from Amaze. An extensive co-design process was undertaken, and from there the pilot project emerged (Appendix 7.1). The pilot developed a one-to-one peer support program for families and carers of autistic children with complex needs. The pilot was designed to utilise a co-design, family-centred approach whereby key community members provide ongoing input and participation throughout each development stage to ensure that their direct needs are being represented. The Autism Peer Assist Pilot project seeks to improve understanding of the ways of supporting people with Autism and their families and carers. The purpose of this support is to target families with complex support needs and to determine if a 1:1 peer support program will address the experiences of this group (such as isolation, loneliness and lack of empathetic support).

The overall aim of the project is to help increase the overall quality of life for carers and family members by reducing their sense of social isolation and to support them through significant challenges as primary carers. In the short term, the project aims to provide emotional support to primary care givers and reduce feelings of isolation. In the medium term, the program aims to address challenges the carer faces within their role and provide information and strategies to address these challenges. Additionally, the project can assist with referrals. In the long term, the project aims to equip care givers with strategies in navigating support services and handling complex needs. As well as this, this project has a focus on improving the carers wellbeing and coping strategies.

The Melbourne Disability Institute (MDI), through its community-based research funding scheme, contracted the Centre for Program Evaluation (CPE) at The University of Melbourne to conduct an evaluation of the Autism Peer Assist Pilot project in September 2021. The evaluation brief was to examine the impact of the project on staff members and participants who are involved in the Amaze program. Amaze will use the outcomes of this evaluation to identify potential areas for improvement and to refine subsequent iterations of the program.

* 1. The Evaluation of the Autism Peer Assist Pilot Project
		1. Purpose of the Evaluation

The aim of this evaluation was to examine the implementation and impact of the Autism Peer Assist Pilot Project, with a focus on capturing and understanding the process as well as the experiences of participants. The evaluation also examined the sustainability of the current model and provides recommendations for further improvement and development.

* + 1. Key Evaluation Questions

The following evaluation questions guided initial data collection and analysis:

1. How has the pilot project been implemented in 2022?
2. What makes it effective?
3. What processes could be refined?
4. What are the main outcomes for primary carers or family members?
5. What are the key recommendations for the next iteration of the project?
	* 1. Program Theory

The evaluation is underpinned by a program logic model or outcome model (Appendix 7.2), which outlines what the program will do and how it will do it. It is a visual representation of the underlying program theory, depicting the sequence of steps by which the intended outcomes will be achieved (Owen, 2006). A program logic model is developed by collecting data from stakeholders about their vision for the project, their inputs, activities and perceived outcomes, and the factors that enable or act as barriers to the program. A thorough understanding of program aims, objectives, inputs, processes, outputs and outcomes are essential to enable the evaluation team to effectively measure and describe the progress of an initiative, as well as make recommendations to support its ongoing development.

To prepare the program logic model, CPE conducted a program logic workshop with staff from the Autism Peer Assist Pilot project in December 2021.

1. Methodology
	1. Evaluation Design

The evaluation focused on the implementation, effectiveness, and impact of the peer support project. This evaluation examined both the process (how the peer assist pilot was implemented and established) and the impact (initial outcomes) of the 1:1 peer support pilot project. Findings from this evaluation will allow Amaze to identify potential areas for improvement and refine subsequent iterations of the project.

* 1. Evaluation Methods

We employed a mixed-methods approach, whereby the Autism Peer Assist Pilot Project was the evaluand for the duration of the project. This approach allowed the evaluation team to analyse and interpret both quantitative (survey data) and qualitative (interview data) findings relating to the project as a whole. (It is noted that Amaze also collected demographic and profile data for the duration of the project). To achieve the above objectives, we employed the following evaluation activities:

A half-day project logic workshop was undertaken with key staff and stakeholders at Amaze. In this workshop, participants discussed project activities and inputs, expected project outcomes (short, medium, and long term) and indicators, and assumptions/limitations to be taken into account in the evaluation of the project. A program logic or theory of change was produced which has informed evaluation design.

* There were 35 referrals into the project. Analysis of data collected via Amaze which included demographic as well as participants’ self-reported assessments of their 10 sessions on a number of dimensions, providing a score when they commenced and a score at the end of the ten sessions.
* An end of project online survey implemented by The University of Melbourne, which included data on project effectiveness, and participants’ perceptions about the pilot.
* Interviews with the Peer Mentors, (2) and the primary carers (5).

It was conveyed to the groups of stakeholders that the researchers were the only people having access to these interviews. Survey and interview data were de-identified prior to analysis.

The figure below summarises the evaluation methodology:

Figure 1. Methodology Overview

* + 1. Data Collection and Analysis

***Interviews***

Interviews were conducted with the two Peer Mentors as well as five interviews with primary carers. The senior evaluator conducted the interviews. All Zoom interviews were audio-recorded (with participant consent) and transcribed prior to analysis.

***End of Project Surveys***

A total of 14 primary carers completed a survey on their views of the program and experiences as participants. The survey was administered from The University of Melbourne, after the carers 10-week sessions. The survey data was collected via a package named Qualtrics and analysed separately and then mixed with the qualitative data.

Table 1. Evaluation Participants – Interviews and Surveys

|  |  |  |
| --- | --- | --- |
| Stakeholder Group | Type | Number of Participants |
| Peer Mentors | Interview | n=2 |
| Primary Carers | Interview | n=5 |
| Primary Carers | Survey | n=14 |

The analysis of qualitative data followed a general inductive approach, where data collected through interviews and focus groups were condensed and thematically analysed using the evaluation questions as focus areas (Thomas, 2006).

* + 1. COVID-19 Pandemic

It should be acknowledged at this point, that this project was undertaken during the COVID-19 pandemic. COVID-19 did not have a negative effect on the project; in fact, one of the advantages was that it got the participants used to Zoom sessions. The only negative effect was that some carers had to postpone their sessions due to COVID-19 illness and sometimes the recovery affected their coping ability. This increased the time period in which the 10 sessions occurred.

1. Results

The results section presents findings from the analysis of demographic and well-being data, interview data, session feedback data and survey data.

* 1. Demographic and Well-Being Data collected from Participants in the Autism Peer Assist Pilot Project

This data was collected by the Peer Mentors in the Autism Assist Pilot Project to provide a profile of the participants in the pilot, as detailed below:

Out of the 35 referrals into the project, 22 participants completed the demographic and well-being measurement questions. Three participants were referred to Amaze through Alfred CYMHS, seven through Autism Connect, one through Carer Gateway, three through the NDIS workshop, one through Lilydale Youth Hub, one through Merri Health and six through self-referral via the Amaze e-newsletter.

* + 1. Demographic data

Participants came from multiple language and cultural backgrounds including Albanian, Indian, Ethiopian, Greek and Chinese. One participant reported using four different languages at home and one participant reported no cultural diversity. Twelve participants did not respond to the language and cultural diversity question.

Eighteen participants have one child with ASD, one of them has another child pending ASD assessment. Four participants have two children with ASD. One participant has a child with ASD and possibly all members of the family have ASD. The children with ASD are aged between 3 to 16.

Participants were in four different states and territory, across both metropolitan and regional areas as shown in Figure 2.

Figure 2. Location of participants in the Autism Peer Assist Pilot Project (n=22)

Information on main source of income was quite varied and not completed for all participants. The data show five participants have a single income, and two participants are a dual-income family. Other sources of income include part-time work, Centrelink payments, pension, and disability pension. Participants reported working from home, working in nursing, and insurance and teaching (retired). Other participants reported studying, being on leave from work or being unable to work.

All participants have at least one complex need. Ten participants have two complex needs, and one participant has three complex needs. Having multiple children with disabilities and/or being a sole carer was the most common complex need among participants (n=13), followed by autistic child presenting behaviours of concern (n=9), carer being autistic themselves and/or presence of a disability, mental health issue, chronic health condition (n=7), carer has experienced trauma or neglect (n=3), carer is from a marginalised background (n=1) and carer experiences social isolation and/or lacking a support network (n=1). Factors of complexity within living arrangement was not reported as a complex need (n=0).

* + 1. Well-being data

The well-being data consist of five areas of assessment, including Caring role, Managing at home, Self-care, Health and Stress and anxiety. Eleven of the 22 participants completed all 10 sessions and initial and final wellbeing assessments. Most of the participants showed improvement across all five areas (Figure 3).

Figure 3. Wellbeing data for participants who completed the program (10 sessions).

Another 12 participants completed five or more sessions, 11 of them completed the initial and final wellbeing assessments. Most participants showed no progress for four areas except for self-care, where there were six participants who showed improvement compared to five who showed no progress (Figure 4).

Figure 4. Wellbeing data for participants who partially completed the program (5-9 sessions).

Overall, five participants showed improvement in all five areas, four participants showed improvement in four areas, four participants showed improvement in three areas, four participants showed improvement in two areas, two participants showed improvement in one area and three participants showed decline or no progress in all areas (Figure 5).

Figure 5. Overall improvement in wellbeing for participants who completed or partially completed the program (n=22).

* 1. Analysis of the Interview and Other Qualitative Data
		1. Interviews with Peer Mentors

The two peer mentors were interviewed separately as part of the evaluation process.

**Experiences running the pilot project**

For both facilitators their experiences in the pilot project were enhanced by seeing the carers grow as they developed their understanding, self-awareness and confidence; plus the feeling of validation that something worthwhile is happening. An important take-away from the project for the carers:

 *Need to remember to breathe! (Peer mentor interview)*

**Positive aspects**

The best things were the peer mentor’s ability to give the carers connections to people and organisations who understand their world, and to be part of their journey.

**Challenges or issues**

The challenges for both peer mentors were very similar. This project was built from scratch so there were no clear guidelines, nor was the software fully developed. Another challenge was the fact that because the carers have busy and complex lives, there was a lot of “no-shows”, and not a lot could be done about that; the limits on the 2-year diagnosis was also restrictive; and as well, the 10-session limit could have been expanded for some clients.

**What worked well**

For both peer mentors the collaboration between the two of them has been the aspect which has worked well. Particularly as they both deal with a lot of complexities.

**Areas for improvement**

A number of administrative areas were identified for improvement. Particularly the software for recording the session data and obtaining suitable software which can protect the privacy of the clients. One of the peer mentors commented that changes needed to be made to some of the questions provided to clients. It was also pointed out that allowing 30 minutes between clients is preferable as well as providing time for admin issues during the week.

**Suggestions of activities to include in the future**

A suggestion was for further training on LGBTIQA+ and domestic violence for APA peer mentors.

**Recommendations for next iterations of the project**

There were a number of recommendations suggested by the peer mentors. Certainly, taking out the need for a diagnosis in the past two years. As well, to think of the carer as a carer of an autistic individual, regardless of the age of the child. One of the mentors would like greater collaboration on the project with higher management.

**Additional comments**

As was pointed out by a peer mentor, it is important to balance the number of sessions required with the requirement for the client not to be reliant on the peer mentor, as the primary aim is for the carer to improve their resilience and confidence. An important consideration is also the documentation regarding processes and knowing what data to collect and when.

* + 1. Interviews with Primary Carers

Five primary carers were interviewed for this evaluation. All participants who left their contact details at the end of the survey, indicating that they would be happy to be interviewed were contacted by the evaluators. The following are the responses to the questions:

**Reasons why they joined the Autism Peer Assist Project**

For all participants they joined the project when the assessment was made for their child/children. One participant was automatically referred by the youth program her daughter had attended. For some that was a matter of months, for others it was over two years ago. All participants spoke highly of the project and the importance for them to understand autism: that understanding leads to empowerment. For one participant it was a shock to receive the diagnosis, as they had little understanding of autism. A couple of participants appreciated the help with the National Disability Insurance Scheme (NDIS) and understanding the process of how to apply for funds. All appreciated the knowledge of the peer facilitators.

**Participant experiences**

For one participant she felt supported in her grieving process. Not only the grief from the autism diagnosis, but her daughter is also trans-gender:

 *So the life we had planned for my girl did not happen. (Primary Carer Interview)*

They all appreciated the help they received with normalising the situation, and all commented how valuable it was to have someone who understood them.

One participant commented how great it was to talk to someone who had understood her situation, and in fact had personal experience.

All participants felt that they came out of the sessions feeling good and positive. One participant commented that they were impressed that the facilitator had answers to their problems. The carer commented that her daughter refused to have her second COVID-19 vaccination, so the facilitator suggested a certain clinic at a hospital who could vaccinate. This was achieved:

 *Now I know that if I am stuck, I can ring Amaze! (Primary Carer Interview)*

**Issues/challenges in being part of the sessions**

Although it was a challenge to receive the news, one of the participants talked about the advice received from the facilitator around what it means to have a trans child who is also autistic. This participant learnt about how to further her knowledge –and this carer is now undertaking further training. Another participant talked about the difficulties fitting in the sessions into a busy life. Another participant suggested that a more structured approach to the sessions could be a benefit. One participant talked about the relief she felt when the diagnosis of Autism was given to her daughter. Previously, there had been barriers and misunderstandings in the relationship. Now she had a clearer understanding of her daughter and her needs:

*I understand why my daughter goes into her room for 3 hours. After school she needs time to come down. (Primary Carer Interview)*

**Skills developed during the sessions**

All of the participants commented on the strategies they were all taught to cope with the different behaviours they encountered. What they were developing in themselves was a greater understanding of the situation which is empowering for them. Also the ability to know where to go if you need information or services. Several participants commented that they would have preferred extra sessions.

**Aspects they would like to see included in the sessions**

One participant commented that they would have liked to have more information on the hereditary factors with autism. Family sessions would have been advantageous for this person. Most people were happy with the information they received, although a few commented that a few extra sessions would have been good. Another participant commented that they would have preferred more structure in the sessions. For example, set topics for the weeks.

**Additional comments**

All participants were unanimous in their praise of the project and the help they had received and would all recommend the project to others. Several participants commented favourably on the flexibility shown by the peer mentors in scheduling appointments.

* + 1. Additional Carer feedback

Twenty Primary Carers were asked the question: “What do you feel the Peer Assist Project has helped you with most?”. The responses received by peer mentors were categorised into themes. The results are as follows:

**Understanding Autism** – Eleven participants commented that the sessions had helped them to understand autism which meant they had a better understanding of their child as well as themselves. This gave them the tools to understand what autism means and how to work through the various and complex issues.

**Learning new and different strategies** – The sessions enabled participants to identify strategies to help their children as well as themselves. This information helped carers understand things differently from the various perspectives.

**Feeling supported and guided** – The largest category (15) were participants who felt supported by the project. They appreciated the non-judgemental approach, and the guide and support was most appreciated. It also gave carers confidence in themselves, and it was a great boost knowing that they were not alone.

**Knowing where to go for support** – Another important aspect of the sessions was the knowledge of where to go for support if needed. This was invaluable for the carers.

**Normalising the Situation** – Several carers noted that the information they were given helped them to normalise the situation at home.

Generally, the carers were most appreciative of the support they received. Several carers talked about the grieving process they experienced, both for themselves as well as their partners, and the strength they received from the peer mentors to empower them to accept the situation they were in. But more importantly to know where to go to get more help. A number of carers would have liked more sessions – or the option of more sessions.

* 1. Analysis of Survey Data

Most respondents strongly agreed or agreed that their peer mentor understood their situation, listened to them when they talked about their personal situation at home, and gave them relevant information (Figure 6).

Figure 6. Participant feedback on peer mentor support (n=14).

Most respondents considered 10 sessions just enough, a few respondents considered them too little, and one respondent considered them too much (Figure 7).

Figure 7. Participant feedback on the number of sessions (n=14).

Most respondents strongly agreed or agreed that the pilot project met their expectations, that the program supported them to understand their care role and the importance of self-care better and feel confident to connect with other services (Figure 8).

Figure 8. Participant feedback on the project and potential impact of the program (n=14).

Respondents would have liked more information on their caring role and self-care, lived experience as a carer, completing the NDIS funding application and school refusal. One respondent would like to have more support sessions in addition to the 10 sessions.

All respondents indicated that they would recommend the project to others because they found it very helpful, supportive, encouraging and non-judgemental. One respondent described the project as a life saver. It was commented that the project was a great opportunity to connect with a mentor with lived experience and knowledge in the area. One respondent reported that the quality of the sessions was consistent throughout and there was flexibility with scheduling the sessions.

When asked what the best part was about being in the pilot, a major theme which came through was being able to talk to someone who has similar experience and who understands their situation:

*Feeling heard/seen. (Survey respondent)*

Another highlight was having gained knowledge about support services that carers of autistic children can access and thus not feeling as isolated as before participating in the project.

Two respondents considered their peer mentor “fantastic” and “amazing” whereas one respondent commented that their peer mentor needs to be more empathetic and not sounding like giving instructions. It was suggested that the sessions can be a little more structured rather than always depending on the mentee to prepare a topic.

One respondent was hopeful that another family member would also benefit from the project and another respondent felt that it should be offered to all carers of autistic children. One respondent mentioned that their mentor organised carer support for them, but it was withdrawn at the end of the peer support project. Overall, the feedback was very positive with a few suggestions to better cater for participants’ needs.

**Table 2. Summary of Key Findings: Autism Peer Assist Pilot Project**

| Evaluation Questions | Key Findings | Interviews Peer Mentors | Well-being dataParticipants | Interviews Participants | Survey Participants |
| --- | --- | --- | --- | --- | --- |
| How has the project been implemented in 2022? | The pilot project was implemented successfully | Challenges with software/adminEffective collaboration between the peer mentorsPilot project provided key areas of improvement | Improvement shown in all areas of assessment | All interviewees appreciated the knowledge of the peer mentors.All participants felt supported by the peer mentorsAll participants felt they had developed coping strategiesAll participants commented that their knowledge of support services had increased |  |
| What makes it effective? | Empathy & understanding of peer mentors | Watching the carers grow as they develop their self-confidence | Monitoring of wellbeing data to identify areas for improvement | Great to talk to someone (peer mentors) who understood their situation.The peer mentors’ knowledge and understanding of the carers’ lives | Participants reported strong empathy & understanding from Peer Mentors |
| What processes could be refined? | Structure & Administration | Need for clearer guidelines & enhanced software.Removal of the 2-year diagnosis requirements. Closer cooperation with managers on the project.More flexibility in the 10-session limit for carers. | Need to refine the health categories in the wellbeing data instrument | For some carers more structure in the sessions would be preferred (i.e., set topics for the weeks) | For some participants, more structure in the sessions would be preferable |
| What are the main outcomes for primary carers or family members? | Increased knowledge of what autism means and how to access support services |  |  | Increased knowledge of support services that can be accessedIncreased understanding of how to deal with a child with autism | Participants felt empowered to connect with other services as required |

1. Conclusion

Although the numbers of responses were small in terms of input from the participants of the project, this was a pilot project, and the representation was high from the small number. There were 35 referrals into the project and 22 completed the demographic and well-being assessments.

As a pilot project this can be considered a success. The participants involved in the project felt supported by the peer mentors and the empathy extended by them was appreciated by the carers involved. A factor underpinning the success of the project was that the peer mentors had similar experiences to those of the carers, and this would be considered essential to any future iterations of the project:

*Connecting with [mentor] (who has autistic kids and is autistic [themself]). Hearing the perspective of someone else who has been through it and who gets it has been great. (Survey respondent)*

The value of peer mentors who have had (or are having) similar experiences to the carers they communicate with, is that the peer mentors can discuss the actuality of having a child with autism:

*I felt I was talking to someone who was walking the talk.* (Primary Carer Interview)

For some carers, the diagnosis of autism was a new phenomenon for them, but after the initial shock, some of the carers were not only accepting of the condition, but active in understanding what autism is and what is means for them and their family:

*“I learnt to be a detective and start to understand what autism in girls look like.” (Primary Carer Interview)*

The carers interviewed confirmed that their knowledge of support services had increased, and they agreed that they felt more empowered to connect with help when it was required.

There are a couple of areas where changes to the project could be made. The peer mentors suggested that the 2-year diagnosis requirement for acceptance to the program be removed. Also, the health categories in the wellbeing data instrument could do with re-working as they are not working as they should be. The peer mentors as well as the carers themselves felt that there should be more flexibility in the 10 sessions limit for carers. Each case of course is individual, but for some carers 10 sessions are enough and for others a few more sessions would consolidate their knowledge. The peer mentors also suggested that the guidelines for the sessions be negotiated with the peer mentored and the carers, and then re-drafted, and that the software for the course sessions be upgraded.

Several carers suggested that the sessions with the peer mentors should have more structure, i.e. set topics for the sessions. Of course, for some carers they would prefer an unstructured session, so perhaps this is something which can be negotiated with the carers at the outset.

1. Recommendations

There are a few areas where recommendations can be considered:

* It is suggested that the requirement for a 2-year autism diagnosis as a requirement for entry into the project be removed
* It is suggested that changes to the wellbeing data collection instrument be undertaken before the next iteration of the project.
* It is suggested that more flexibility in the ten-week limit for the sessions with carers be considered
* It is suggested that consideration be given to a more structured approach to the delivery of the sessions: perhaps introduce the idea at the first session with Carers.
* It is suggested that one of the main components of the program, i.e. including peer mentors with lived experience be retained, as it is a vital element of the project
* It is suggested that, taking the above into consideration, that changes be made to the guidelines for the project, as well as an upgrade of the software.
1. References

Owen, J.M. 2006 Program Evaluation: Forms and Approaches. 3rd Edition. Allen & Unwin. Sydney. Australia.

Thomas, D. R. (2006). A general inductive approach for analysing qualitative evaluation data. American Journal of Evaluation, 27(2), 237-246.

1. Appendices
	1. Co-Design Group – Topics Covered

**Introduction**

The Autism Peer Assist Pilot Project utilised a Co-Design Group which met four times in 2021. The main focus of the group was to anticipate and discuss some of the perceived issues/challenges which face a carer or parent in the early stages of the autism diagnosis, as well as thinking through and designing how the sessions were to be run.

The membership of the group was broad – including the funder of the project, peer leaders, Amaze staff, some external community members with lived experience and two psychology students.

The first meeting of the co-design group discussed the challenges which are faced by a parent or carer after the diagnosis of autism. Issues such as:

* Managing finances
* Where to go for support
* Individualising Grief
* Work life balance
* Self-care
* Managing other people’s reactions and perceptions
* Dealing with feeling overwhelmed

The group also discussed some ideas for project delivery with the main focus on the care of the carer. Resources for carers were discussed, with the main emphasis being on ensuring that the carer was not overwhelmed by materials. It was decided that the best way would be to send the carer a list of the resources available, and then leave it to them to decide if and when they needed them.

The group then defined complex needs and decided that the term should refer to the carer’s as well as the child’s needs. In terms of who is included in the pilot project it was agreed that the project would support carer’s of children aged 18 or below.

It was also agreed that poverty and diversity training would be given to all peer mentors to increase their knowledge and understanding. In terms of the delivery of the pilot, it was agreed that the content would be driven by the carer’s needs and goals. The carers would have the option of either phone or video contact from their peer mentor.

Confidentiality was another issue discussed during the sessions. It was agreed that peer mentors’ personal identity and details will remain confidential by using a registered Amaze email and phone number to contact participants. It was also agreed that participants will have the same peer mentor throughout the project to aid rapport building and increase quality of support as participants will not have to repeat themselves. Another important issue was that peer mentors do have a duty of care to report any incidents of potential abuse and criminal activity. The peer mentors will also have extensive policy and procedure training.

It was agreed that in terms of disclosure of information, although it is important to build trust with their mentees, that mentors do not overburden the mentee with excess information, particularly of a personal nature.

It was also agreed that Peer Mentors would receive professional supervision and access to counselling support throughout the project. This would help them to offload any issues which affects them. Peer mentors would also receive ongoing feedback from supervision team.

The final session discussed training, recruitment and hiring as well as how to deal with conflicts of interest. There was also a discussion of the Kubler-Ross model of the stages of grief, and situations where specific training would be required.

Peer mentors were also asked to complete a feedback sheet which would help Amaze understand which areas require improvement.

* 1.
	2. Program Logic Framework

Pilot project — Autism Peer Assist Project (which is a one-to-one peer support service for primary carers of autistic children between the ages of 0-18 who have received a recent diagnosis of autism within the last two years and have been deemed to have complex support needs).

| **Inputs** |  | **Outputs** |  | **Outcomes - Impact** |
| --- | --- | --- | --- | --- |
|  | *Activities* | *Participation* |  | Short (6 months) | Medium (18 months) | Long |
| Staff knowledge Tools and resources created by AMAZE and othersEnabling technologyStaff time, both paid and unpaidVolunteersPrimary carersNetworks for referralsMentors with lived experience |  | One-on-one mentoringDevelopment of practice guideDevelopment of tools and processesStaff trainingPromotion to referral networksCo-design team activitiesTriage families into this and other peer support programs | Primary carersCommunity membersCo-design teamPeer mentorsAMAZE staff |  | Identifying practices and an effective, sustainable model of supportEmpowering primary carers to access services and self-advocateIncreased primary carer knowledge Connections to peer supportImproved primary carer mental healthCarers feel validated and understood | Models and frameworks for a sustainable 1:1 peer support program | Increased quality of life for carers and family membersImproved outcomes and experiences for children with autism and their familiesImproved knowledge for children with autism and familiesImproved satisfaction and health experiences for families/carersEmploying more peer mentorsExpanding the program as an ongoing support service for primary carers |

**Improved outcomes and experiences for primary carers of autistic children**

|  |  |  |
| --- | --- | --- |
| **Assumptions**e.g. That the one-to-one peer mentor project will improve the overall quality of life of primary carers |  | **External Factor**NDIS (contextual factor that will influence success of carers)Schools TherapistsInformal supports (i.e., grandparents, friends and family)Household structureCommunity services (allied health) |

**7.3 Questions for Peer Mentors and Primary Carers**

**Semi Structured Final Interview Questions for Primary Carers and Peer Mentors/Amaze Staff (draft)**

**Primary Carers**

1. Could you tell me about why you joined the Autism Peer Assist Project?

2. Tell me about your experiences in those ten sessions? (*ie. What went well, did you feel supported, was there anything else that could have been done?)*

3. Did you have any issues/challenges being part of the sessions?

4. What skills did you develop during your sessions? (*probe for greater confidence, better advocate for child etc. able to access information as needed)*

5. Was there anything you would have liked to discuss that was not covered?

6. Are there any other areas which you would like to comment on?

**Thank you for your time**

**Interviews with Peer Mentors/Amaze staff**

1. Were there any challenges or issues for you in running these sessions?

2. What do you think has worked well in those sessions?

3. Are there areas you have identified for improvement?

4. What are your thoughts on any recommendations for the next iteration of the project?

5. Do you feel you were supported in your role?

6. Have you any final comments

**Thanks for your time**

* 1. Survey Question for Primary Carers

Now you have completed the ten sessions of the Autism Peer Assist Project, we would like to ask you to complete this short questionnaire. Your answers will assist Amaze to make any changes to the program. Thank you in advance for your input!

 ……………………………………………….

**The Peer Mentor/s**

1. I was well matched to my peer mentor? (SD to SA)

2. The peer mentor listened to me when I talked about my situation (SD to SA)

3. The peer mentor gave me relevant information (SD to SA)

**The Autism Peer Assist Pilot Program**

4. In terms of the number of sessions, was 10 (too much) 🞏 (too little) 🞏

(just enough) 🞏

Comments: …………………………………………………………………………………………………

5. I was able to achieve my goals? (SD to SA)

6. The pilot project met my expectations? (SD to SA)

7. I feel I can advocate for my child better now? (SD to SA)

8. I feel confident to connect with the services I need: (SD to SA)

9. Are there other areas you would have liked more information on?

Comments: …………………………………………………………………………………………………

10. Would you recommend this project to others and why?

Comments: ………………………………………………………………………………………………………..

11. What was the best part about being in the project?

Comments: ……………………………………………………………………………………………………….

12. Is there anything else you would like to comment on?

Comments …………………………………………………………………………………………………………..

We may like to use your comments in our promotional materials.

Please indicate here if you give us permission to use them: YES 🞏 NO 🞏

If YES, would you like your comments to be (please tick one):

1) Unattributed (your comments would be anonymous)   🞏

2) Attributed (just your name would be provided)   🞏

Name: Email/Phone No.

If you have provided your details, would you indicate if you would like to be part of a short online interview to provide further information about your experience in the peer assist pilot project.

YES 🞏 NO 🞏

Thank you for your time

-



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