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Dear NDIS Independent Review Panel

My name is Dr James Ong. I am the Evaluation and Policy Manager of I CAN Network Ltd. On behalf of the I CAN Network, I would like to thank you for giving us the opportunity to provide a submission to the National Disability Insurance Scheme (NDIS) Review.

I CAN Network is an Autistic-led organisation that is pursuing a vision of 'a world that embraces Autism' by running programs 'to prove what Autistic people CAN do'. Our most notable programs are our school and online peer mentoring programs which aim to build social connections and improve the self-esteem of Autistic young people aged 8-22 years.

I CAN ONLINE OVERVIEW

I CAN Network runs the online mentoring programs via I CAN Online. Each year, I CAN Online runs seven cycles of six weekly one-hour sessions delivered in either the afternoon or evening. Within each cycle are multiple online mentoring groups catering to different special interests, with each group consisting of nine Autistic young people and two mentoring staff. The programs are priced at $291 per Autistic young person. Families can also request an NDIS progress report detailing the changes their Autistic young person experienced in the online mentoring programs at $169.50 each.

The online mentoring programs have a strong focus on social skill development, increased self-worth and confidence, Autistic pride and self-acceptance. There is a strong focus on social connection, the skills required to engage in conversations and the conventions that sustain a conversation. Within these sessions, we weave discussions around Autism, emotional regulation and problem-solving into the questions in a subtle and themed way.

The group also provides a safe environment for participants to learn how to deal with conflict and differing opinions and views and what emotional regulation and sensory strategies can assist them when these moments occur. Our staff are predominantly Autistic, meaning we can provide support related to NDIS participant goals that are based on Autistic processing and lived experience. Furthermore, we provide a unique connection that will hopefully foster an increased sense of self-worth, self-esteem and confidence that can translate to other life areas. These are all reflected in the NDIS reports that we write for the Autistic young person's families.

From our experiences in running I CAN Online, we have gained some insights on the NDIS that we would like to share with you. These insights describe not only the running of online mentoring programs, but also the engagement of parents who use the NDIS to support their young person's participation in our online mentoring programs.

CONTENTS PAGE

I CAN ONLINE OVERVIEW 1
EVALUATION OF NDIS INITIATIVES 3
EMBRACING STRENGTHS-BASED APPROACHES 4
CONTINUING AND GROWING THE INFORMATION, LINKAGES AND CAPACITY BUILDING INITIATIVE 8
OBSERVATIONS OF NDIS PLANS INCLUDING I CAN'S SERVICES 10
CONCLUSION 11

EVALUATION OF NDIS INITIATIVES

…through a renewed focus on evidence and data – we can get rid of shoddy therapies that offer little to no value to participants or desperate parents…

The Hon Bill Shorten MP, Minister for the NDIS, Address to the National Press Club, 18th April 2023

Within the NDIS, there is a renewed focus on obtaining evidence and data on the outcomes of NDIS-funded programs to assess their effectiveness and value for money. Since I CAN Network's establishment, outcome measurement is inherent in our work as we have been running internal evaluations to measure the implementation and effectiveness of our programs. Results from these evaluations have been used to inform further improvements to our programs and to build an evidence base behind our programs. Internal evaluations are a central part of our work, with an Evaluation Manager coordinating them. We are proud to report on the social impact of our work to stakeholders and the public, highlighted by us creating and making our social impact reports available to the public every year.

Hence, we welcome the increased focus on the evidence base behind NDIS-funded programs and therapies which will allow effective programs and initiatives to continue to be funded by the NDIS while removing those that show little or no value to NDIS recipients. At the same time, there is a need for greater flexibility on how we report on the outputs and outcomes of our programs to the Department of Social Services (DSS). Most Autistic young people whom we engage in our online mentoring programs have co-occurring conditions such as anxiety and depression, and some of them have an intellectual disability. Hence, it takes time for us to develop internal evaluation tools that are short, quickly understood by all Autistic young people and do not trigger stress.

During the ILC grant, the Department of Social Services (DSS) gave us a survey that we had to use to measure the outcomes of our program. Although the statements matched the desired outcomes of the Individual Capacity Building Program, we did not use the survey in our mentoring programs as the statements were too long and vague, meaning Autistic young people would be unable to quickly grasp the meaning of the statements. Instead, we matched data from our internal evaluations to some statements in the DSS survey.

Thankfully, the way that ILC programs will be evaluated is changing. We have been consulted on the development of a new Performance Management Framework for ILC grants and how data will be collected and analysed. In particular, there is a move towards grant recipients developing their own evaluation tools and collecting and analysing their own data to measure outcomes. These changes are something that we appreciate as that would allow us to use our existing evaluation tools to present results that suit the needs of both the DSS and the I CAN Network. This flexibility in how we collect and report on our evaluation results needs to continue beyond the NDIS review so that we can tailor our evaluation processes to measure outputs and outcomes in a way that is respectful to Autistic young people.

Simultaneously, more assistance needs to be given to community organisations to measure the outputs and outcomes of their programs. I CAN Network is lucky to have an Evaluation Manager who is dedicated to running internal evaluations of its programs. In contrast, we have heard from different community organisations that they do not have the time, resources or expertise to plan and conduct evaluations. The NDIA and DSS should provide more guidance and resources to community organisations to help them plan and run their own evaluations. In particular, community organisations should be trained on the importance of both quantitative (numerical) and qualitative (descriptive) data to understand the impact of their programs to people with disability and their experiences in the programs respectively. This would not only provide outcome data behind these programs, but would also centralise individual voices and lived experience to delve deeper into how the programs have made a difference to their lives. Both pieces of information are important for reporting on the outcomes of the NDIS.

EMBRACING STRENGTHS-BASED APPROACHES

A strength-based approach is a way of working that focuses on abilities, knowledge and capacities rather than deficits, or things that are lacking… The intention of this approach is not to avoid or minimise problems, challenges or risks… but to identify the assets or strengths that can be built upon and used...
Children and Family Intensive Support, Department of Social Services, April 2022

There is a need for the National Disability Insurance Agency (NDIA) to embrace strengths-based, lived-experience approaches that improve outcomes for people with disability, instead of solely relying on evidence-based supports. From our perspective, the NDIA is strict on the programs and therapies that can be funded by an individual NDIS plan. In addition to showing value for money, the program or therapy has to be evidence-based. Often, the programs and therapies where evidence is present are deficits-based, focusing more on ameliorating the problems people with disability face rather than harnessing their strengths to improve outcomes. Deficits-based approaches also appear in planning and reassessment meetings, where the focus is on what people cannot do rather than celebrating what has been achieved. This can be a stressful and traumatising experience for the NDIS participant and their families.

I CAN Online is a strengths-based approach to Autism that harnesses the lived experiences of Autistic staff to build mentees' self-esteem and social connections and to adapt the mentoring program to their needs. Our online mentoring programs are well-liked by mentees, with 89% mentees indicating that they enjoyed the online mentoring program, and improve outcomes. In a typical six-week cycle, we see positive changes among Autistic young people in terms of how they interact with other mentees and in being themselves in the group (Figure 1). This can be seen by:

- An 18% increase in mentees enjoying meeting other people in their group;
- A 13% increase in mentees being able to chat or share with other people in their group;
- An 11% increase in mentees not having to hide who they are in their group; and
- A 15% increase in mentees feeling supported and respected in their group.

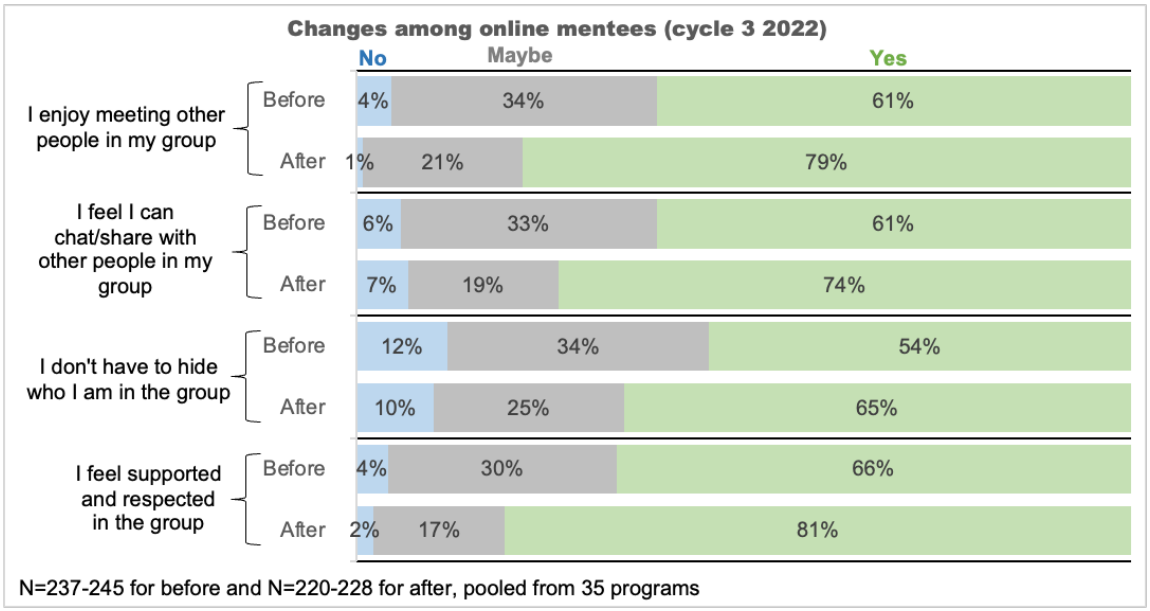


Figure 1: Changes among mentees in a typical six-week cycle for I CAN Online

Additionally, repeated participation of I CAN Online programs can have long-term effects on mentees. As shown in Figure 2, mentees' communication skills before the program gradually improve as they attend more online mentoring programs. This shows that constant participation in I CAN Online programs is key to improving self-esteem and communication skills in the long term. Given that these skills are important for developing Autistic young people's self-expression and self-advocacy skills, this lends support towards the use of NDIS funding to fund multiple cycles of I CAN Online.

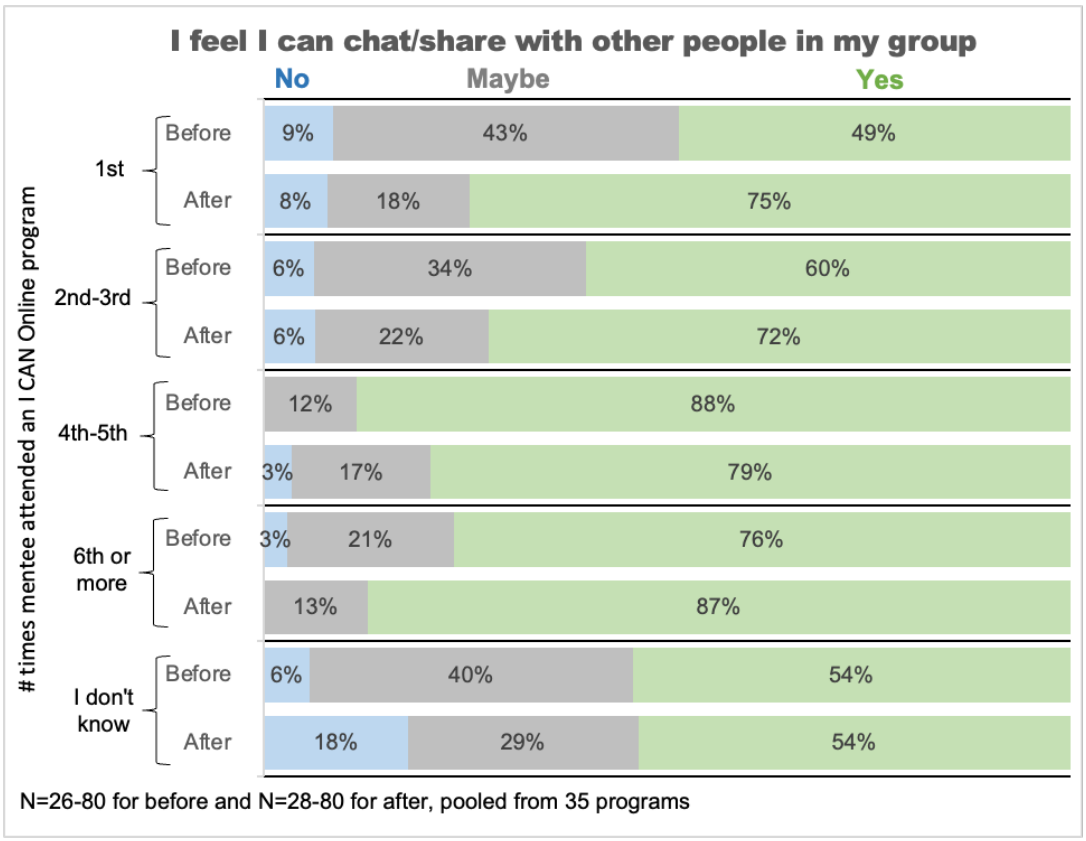
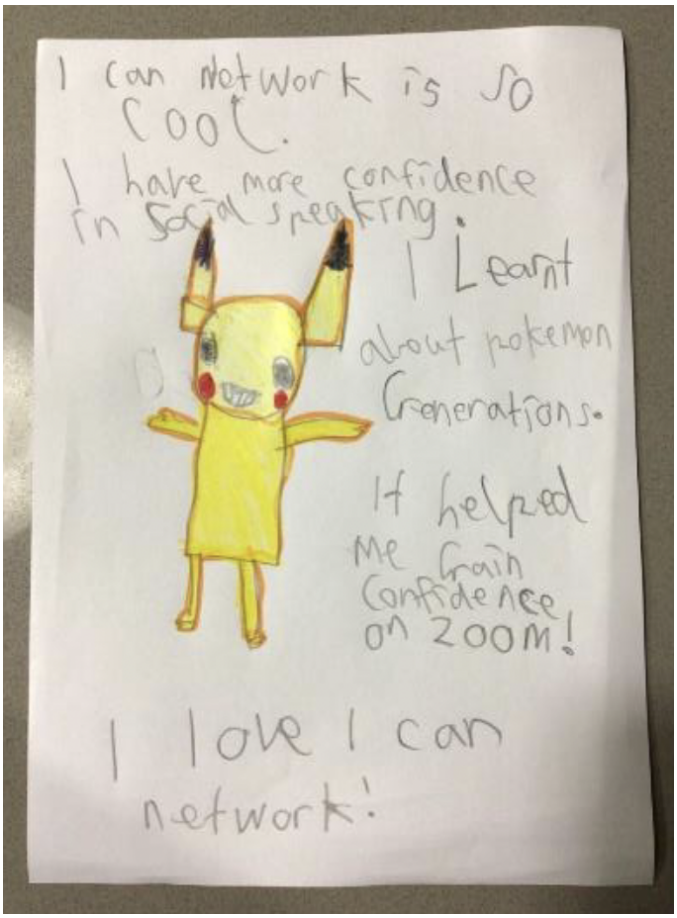


Figure 2: Changes among mentees in communication skills, split by the number of times mentees attended an I CAN Online® program

These quantitative results are backed by comments and creations from mentees and their parents. By creating a group environment which is positive, safe and welcoming, and tailored to their strengths and special interests, mentees are allowed to be themselves, reducing the stress associated with masking their true selves. This is highlighted by one mentee who said that:

"I have been in a lot of social groups. This is the only one that has actually let me be myself. I had to pretend to be someone else [in other social groups] when I really didn't want to, which was really hard. With this [I CAN] group, I managed to build that self confidence in order to be myself."

By being allowed to be themselves and discuss their special interests in the online group, mentees can build their self-confidence and improve their communication skills. This can be seen in the below mentee creation (Figure 3), where the mentee commented that they not only loved the program and learnt more about their special interest in Pokémon, but they also became more confident in communicating with other people online.



"I CAN Network is so cool.
I have more confidence in social speaking.
I learnt about Pokémon Generations.
It helped me gain confidence on Zoom!
I love I CAN Network!"

Figure 3: Drawing from an online mentee.

Another creation from an online mentee describes how they felt a sense of belonging in the online program, where they were allowed to be themselves and make new friends (Figure 4).

Figure 4: Artwork from an online mentee.

Additionally, parents have commented positively on how the online mentoring programs have made a huge difference to their young person's sense of self and mental wellbeing. Parents commented that the online mentoring programs allowed their Autistic young person to normalise their experiences with other like-minded peers, improving their self-esteem and self-acceptance. This allowed one parent to observe that the online mentoring programs "*...gave him [my son] a lot of confidence that he was just like everybody else. He felt comfortable in his own skin and believed us when we told him he was just like everybody else…*". The good news stories run in each mentoring session improved Autistic young people's capabilities in identifying the positive things in their life. This was noted by one parent who said that their Autistic young person learnt that "*...there are many positives in her [my daughter's] life, but also that the focus doesn't need to be on the negatives, which are much smaller in number*". The focus on lived experiences and the positives of being Autistic can improve the mental wellbeing of Autistic young people. One parent commented that their son, who had depression, felt "*...no longer ashamed of who he was. He now speaks openly about autism and no longer sees himself as broken...*".

These outcomes are being achieved among a group of highly vulnerable Autistic young people with high rates of co-occurring conditions (Figure 5). A sizable number of mentees have mental health conditions such as anxiety (87%), depression (26%) and suicidal thoughts (13%). Some Autistic young people also have other neurodivergent conditions such as ADHD (54%) and dyslexia (7%). Given the large focus on mental health supports for people with disability who have psychosocial or mental health issues, we feel that peer support programs are important in building social connections and improving the mental wellbeing of Autistic young people.

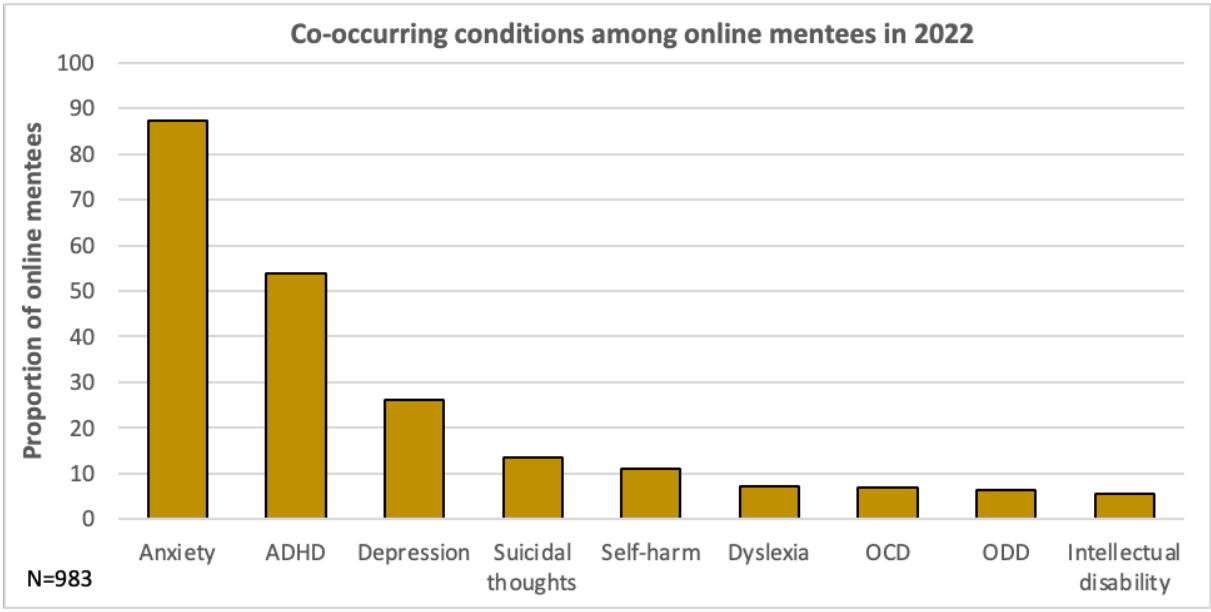


Figure 5: Proportions of online mentees with specific co-occurring conditions in 2022

Collectively, these results show the value of leveraging strengths and lived experiences to improve outcomes for people with disability. We feel that this is something that the NDIA should consider when discussing supports with people with disability.

CONTINUING AND GROWING THE INFORMATION, LINKAGES AND CAPACITY BUILDING INITIATIVE

…The NDIS was not designed to support the needs of all Australians with a disability. There must be adequate disability supports for those people with disability not eligible for the NDIS…
Prof. Bruce Bonyhady AM, Co-chair of Independent Review of the NDIS, 2022 Kenneth Jenkins Oration, 28th November 2022.

As the above quote indicates, the NDIS cannot, by itself, achieve the desired outcomes of all people with disability. They must also be supported by policies and initiatives that build their capacity to live independently and access services, reducing their reliance towards the NDIS which is key to its sustainability.

I CAN sees the Information, Linkages and Capacity Building (ILC) initiative as a very important part of the NDIS. It funds community programs and initiatives that support people with disability regardless of their eligibility for individual NDIS plans. The programs under the ILC initiative aim to build individual capacity and peer support for people with disability to independently participate in life and advocate for themselves while improving accessibility of services and supports for people with disability. Ultimately, successful implementation of the ILC initiative will prevent or reduce the need of all people with disability to have individual plans under the NDIS.

I CAN Network has been a participant of the 'Individual Capacity Building Program' within the ILC initiative since 2020. The I CAN Online programs are in high demand, with waitlists lasting one cycle. Previously, we could only run online mentoring programs in the evening which restricted the number of Autistic young people that we could engage in a six-week cycle. However, funding from the ILC initiative has allowed us to run online mentoring programs in the afternoon which has not only made them more accessible to Autistic young people Australia-wide, but also enabled the expansion of I CAN Online.

We initially aimed to engage at least 50 Autistic young people per cycle in the afternoon. However, we have seen a gradual increase in the number of afternoon online mentoring programs and mentees engaged in these programs. By Cycle 2 2023 (which lasted from May to June 2023), we ran a total of 14 afternoon online mentoring programs for 122 mentees (Figure 6).

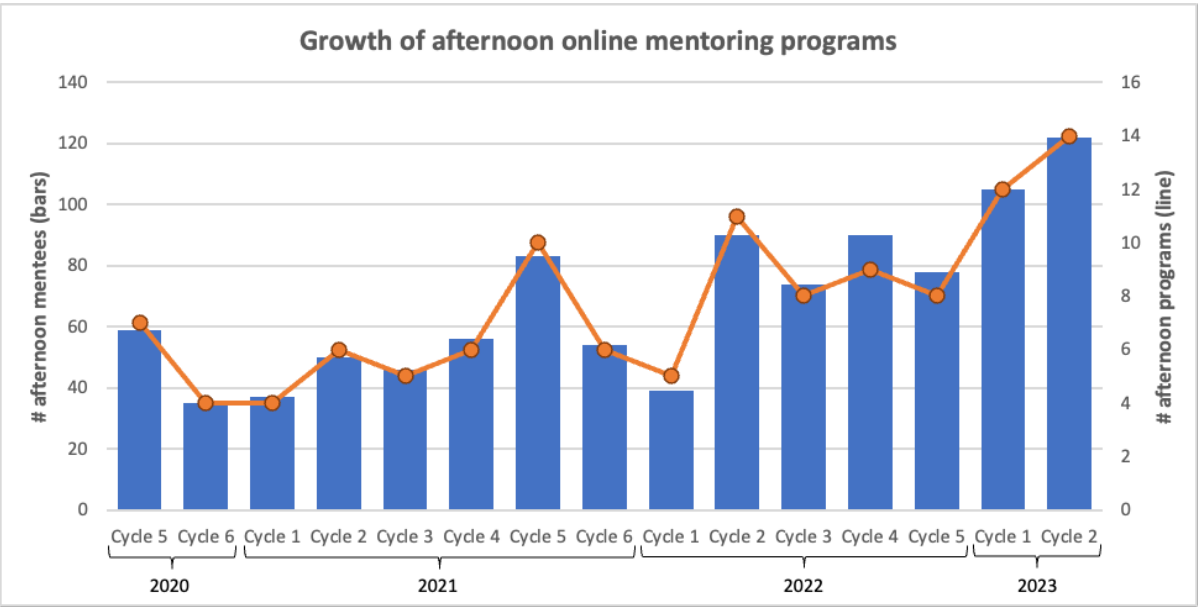


Figure 6: Number of mentees engaged (bars) over a number of afternoon online mentoring programs (line)

The availability of afternoon online mentoring programs has also generated other benefits.

Firstly, making online mentoring programs available in the afternoon frees up some slots in the evening for participants who can only come in the evening. For example, the afternoon online mentoring programs allow more Autistic young people in South Australia and Western Australia to come to the evening online mentoring programs.

Secondly, afternoon online mentoring programs can cater to younger mentees (7-8 years old) who are tired in the evening and need to sleep early. They can attend afternoon online mentoring programs where they can engage with mentors and other mentees while they still have energy.

Lastly, for families where more than one sibling participates in I CAN Online, the younger sibling can participate in the afternoon while the older sibling can participate in the evening. This allows parents to individually support each sibling as they participate in their online mentoring program.

The afternoon online mentoring programs would not have been possible without funding from the ILC initiative to hire more Autistic staff. From a base of 21 Autistic staff in May 2020, we now employ 45 Autistic staff in our online mentoring programs (Figure 7). In turn, by offering afternoon online mentoring programs to mentees, we have been able to offer more sessions and more consistent work hours to our Autistic staff. This has allowed us to retain Autistic staff in our team, keeping them employed. Additionally, funding from the ILC initiative has allowed us to reduce administrative time by hiring and retaining program managers (who supervise the online mentoring programs) and improving our customer relationship management system (‘Salesforce’).

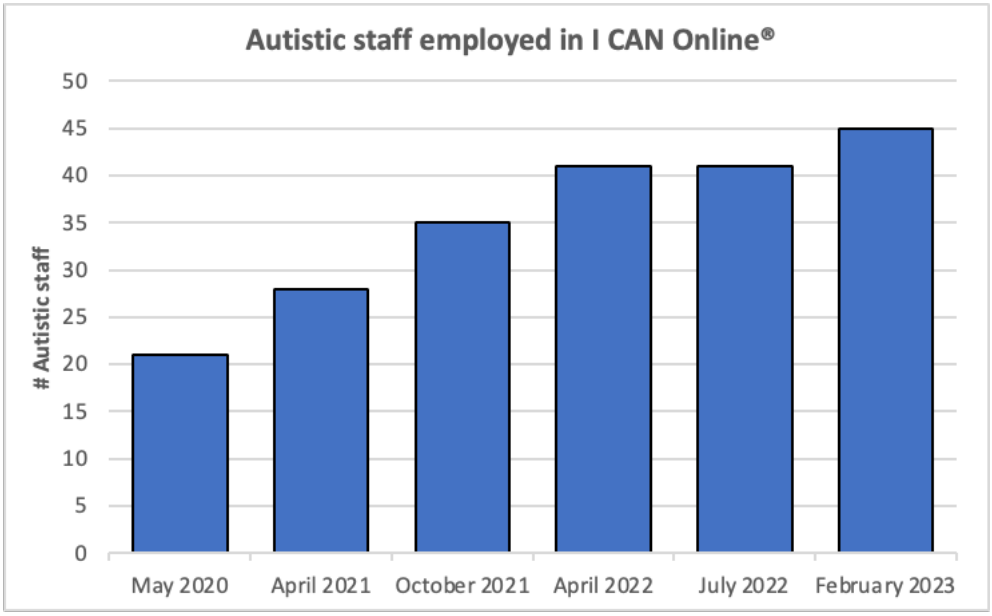


Figure 7: Number of Autistic staff employed in I CAN Online® over 2020-23

Collectively, these results show how valuable the ILC initiative has been to the I CAN Network. Funding from the ILC initiative has allowed us to expand our online mentoring programs so that they are accessible to all Autistic young people across Australia. Without funding from the ILC initiative, we would not have been able to expand I CAN Online®, meaning we would have needed to contend with a growing waitlist of Autistic young people and their families.

This case study highlights the value proposition of the ILC initiative in funding community organisations to support people with disability who are eligible or ineligible for the NDIS. Because of this, the ILC initiative should receive more funding so that community organisations can improve their services for people with disability.

OBSERVATIONS OF NDIS PLANS INCLUDING I CAN'S SERVICES

…while the National Disability Insurance Scheme (NDIS) is a critical source of support for many autistic people, engaging with the National Disability Insurance Agency (NDIA) is a significant source of stress. Indeed, the time and effort required to navigate the NDIS has been described as equivalent to a full-time job.
The Senate Select Committee on Autism final report, March 2022

The NDIS has made I CAN Online more accessible to families of Autistic young people, particularly those of low socioeconomic backgrounds. Without the NDIS, parents would not have been able to send their Autistic young person to multiple cycles of I CAN Online. However, despite the benefits of the NDIS, there are still issues associated with how the NDIS is being administered. In our submission to the Federal Senate Select Committee on Autism in 2020, we cited two issues on how the NDIS is being administered:

1. Parents feeling overwhelmed on how to use their young person's NDIS plans to achieve their goals, with few accessible resources to guide them through the process; and
2. Review meetings being scheduled within a week without warning, causing stress among parents who have to gather reports from their providers.

These issues are linked to our observation that Autistic parents are likely to be overwhelmed by NDIS processes, requiring further assistance. This supplements a point from the 'What we have Heard' report which indicated that NDIS planning processes have to better recognise the needs of NDIS participants with cognitive disability, including Autistic people.

These problems still persist as of 2023. Since our submission in 2020, we have seen an increase in the number of enquiries on how NDIS funding should be used from parents, local area coordinators and plan managers. Although part of the problem could be attributed to an expansion of our online mentoring programs,

there are still communication difficulties on how our online mentoring programs should be coded to describe how NDIS funding was used. Local area coordinators and plan managers who administer provider-managed plans often approach us to get the relevant codes and details of our programs so that they can invoice us and keep records of how NDIS funds were used. Parents who manage their young person's NDIS plans contact us to ask how to categorise I CAN Online in the plan. In both cases, as we are unable to view a young person's plan, we can only provide general advice of which category to use to code I CAN Online programs.

We propose the following solutions to improve how I CAN Online® programs are recorded on an individual NDIS plan. First, service categories need to be simplified so that parents, local area coordinators and plan managers can more easily categorise the I CAN Online program under the appropriate category. Second, simple, accessible guidance documents should be provided to parents, local area coordinators and plan managers so that they know which activities fall under each category. Third, rehashing from our 2020 submission, accessible resources need to be generated and made available to Autistic parents so that they can understand how the NDIS works and manage their young person's NDIS plans without being overwhelmed by a huge amount of information.

The plan review process, now known as plan reassessment, is still stressful to parents. Most NDIS participants have a 2-3 year plan, so they know approximately when a review meeting will take place. However, there are still some cases where review meetings are set one week before the meeting itself. The review process is stressful to the parent who has to gather documents within the week before the review meeting. This also has a trickle-down effect on our online administrative staff who have to gather and read session notes of the young person to prepare an NDIS report for the parent. In rare cases, we get an email from a parent requesting an NDIS report one day before the review meeting itself. Despite recent amendments to the NDIS Act in 2022 to simplify review processes for NDIS participants, more needs to be done to ensure that review meetings are set in advance so that parents have more time to gather the required documents. This will help reduce the stress associated with preparing for the review meeting for both parents and our online administrative staff.

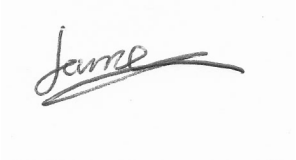
CONCLUSION

Our submission to the NDIS review stems from our experiences in running a successful evidence- and strengths-based program for Autistic young people. From our internal evaluations, we have been able to show the effectiveness of our I CAN Online® programs in leveraging Autistic young people's strengths and special interests to build social connections and improve their social skills and self-worth. This highlights the value of strengths-based programs in producing positive outcomes such as improved mental wellbeing for people with disability who have co-occurring mental health and neurodivergent conditions, as well as the importance of evaluating the effectiveness of NDIS-funded programs.

Furthermore, being a participant of the ILC initiative has allowed us to expand I CAN Online® by recruiting more Autistic staff to run afternoon online mentoring programs. We see the ILC initiative as a worthwhile initiative to fund as it allows community organisations to improve the lives of people with disability. Lastly, from our interactions with parents of I CAN Online® mentees, the NDIS is valuable in supporting their young person's continual participation in I CAN Online. At the same time, more needs to be done to ensure that the administration of the NDIS does not stress parents of Autistic young people.

We hope that you enjoyed reading our submission for the NDIS review. Should you have any questions or enquiries, please contact me at james@icannetwork.com.au.

Yours sincerely



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