

Centre for Inclusive Supports Inc.

Evaluation Report

Pilot Program 2022



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Perceptions of Families, Support Workers and the Facilitator of a Post-Secondary Pilot Program at University for Young Autistic Adults with Intellectual Disability

Summary

Responding to an urgent need to provide post-secondary options for autistic people with intellectual disability, a new day program was piloted in Brisbane city. This paper provides a detailed description of the program's aim, design, content and structure and, in addition, perspectives and main themes which emerged from qualitative data collected from families, support workers and the facilitator. Students in the program included six young male adults. Semi structured interviews were conducted with six support workers, twelve parents, three siblings and one facilitator with 23 in total contributing to the qualitative data collected to ascertain their perceptions of the 6 month pilot. The themes which emerged from the analysis using Leximancer and manual coding included: participation, friendships, program experience, communication, and the role of a carer.

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Introduction

A pilot of a day program aiming to address the disparity of postsecondary options for young autistic adults with intellectual disability which sought to support quality of life, engagement in the community, and mental health and wellbeing of the students and their families is the focus of this paper.

Autism is characterised by differences in social communication, and the presence of restricted and/or repetitive behaviours and/or interests (American Psychiatric Association [APA], 2022). Prevalence is approximately 1.7% in Australia (Salari et al., 2022). In Australia people with permanent and serious disability are eligible for support through the National Disability Insurance Scheme [NDIS] (NDIS, 2021). Two thirds of those NDIS participants are autistic, and it is suggested one third (Maenner, 2021) also have intellectual disability (National Disability Insurance Agency, 2021). However, even with NDIS funding, it can be a struggle to improve outcomes. The Australian Bureau of Statistics (Commonwealth of Australia, 2020) reports more than half of autistic people had a disability with a profound or severe limitation in core activities and 29% are permanently unable to work.

As such, there is an urgent need to provide post-secondary options for autistic people with intellectual disability to support quality of life, engagement in the community and mental health and wellbeing. The purpose of this paper is to describe the program and present findings from preliminary qualitative data collected.



Literature review

There is scant research addressing family and support worker perspectives on postsecondary participation, particularly with respect to autistic students (Widman & Lopez-Reyna, 2020; Smith et al., 2014). We review the current literature in relation to the parents' role in the lives of their autistic adult children and the options for post-secondary further learning for them. After an overview of the current relevant research both locally and internationally we present the research question. Despite the clear role of a parent in supporting the lives of their disabled children (even as adults), it is possible parents are also filling in the gaps left by support services to respond to individual needs and challenges (Widman et al., 2020). In fact, parents are the drivers of a high quality of life after school for their adult children with disability (Smith et al., 2014). In post-school education, where young autistic adults are enrolled students, parents become a source of advice, and often take a leading role in advocating for their needs (Dwyer et al., 2022).


Mothers play a key role in supporting transitions for children and young adults with disability (Strnadová & Evans, 2013). Mothers and fathers are impacted differently by their parenting roles when a child has a disability (Vatne, et al., 2022) and the experiences of fathers remain poorly understood (Paynter, Davies & Beamish, 2018). Mothers are generally reported to be the primary caregivers and their role includes organising appointments, dealing with service providers and NDIS funding, housework, and research (Paynter, et al., 2018).

Transitions represent a heightened period of stress for parents (Smith et al., 2014), and young adults with intellectual disability, as reported by mothers in Strnadová & Evans (2013) They also “referred to behavioural issues as a complicating factor for successful transitions” (p. 75). The challenge of transitioning to life after school is exacerbated when the young adult has a more significant need for support, these young people are more commonly educated in special schools.

The earlier transition of moving from primary education to secondary education is often avoided by these families because their children attend Preparatory Year to Year 12 schools where the campuses are combined allowing the students to “avoid the stress and resulting challenging behaviour brought on by changes in the environments and people” (p. 152, Strnadová, et al., 2016). Anxiety is common for autistic people (Kent & Simonoff, 2017) and this loss of structure and routine after school can have a negative impact on behavioural development for these young adults and present a challenge for families (Smith et al., 2014).

Transition from high School for most Australian students involves moving to further education or the workforce. This is not the case for students with disabilities, particularly those with an intellectual disability (Wedgewood et al., 2023). Many of these students attend a segregated state-run special school. There are 37 of these in the city where this study occurred (Department of Education, 2023). For those people who attend a regular ‘day program’ in a centre, the focus is on independent life skills such as cooking or using public transport (CDA, 2015, p22). In Australia, government funds the development of employability skills through avenues like the School Leavers Employment Supports funding (SLES) and in services such as ‘Skills Disability Support’ (Department of Social Services, 2023). One consideration for improving employment outcomes for autistic individuals with intellectual disability involves training and further education and having individualised and person-centred support available while studying (National Disability Insurance Agency, 2021). Autistic students’ required level of support varies greatly. Interests, cognitive profiles, social skills, strengths and challenges are heterogenous (Test, et al., 2014).





With further learning, there is little choice for autistic people with intellectual disability. Vocational colleges and universities in Australia need to recognise the needs of this population more fully and modify and adapt further learning to suit them (Wedgewood, O'Donovan & Rillotta, 2023). In Australia University programs have been limited. Two such programs at University of Sydney (Uni2Beyond) and Flinders University (Up the Hill Project) implemented course/subject auditing for people to have an experience of university (Wedgewood, O'Donovan, & Rillotta, 2023). Neither were supported by a clear and sustainable funding model, and both were reliant on local support (Wedgewood et al., 2023). At the time of writing, both programs are suspended due to lack of funding and reliance on volunteering (Wedgewood et al., 2023).

In the United States over 300 tertiary institutions are government funded to provide post school disability inclusion programs (Wedgewood, O'Donovan & Rillotta, 2023). A recent and comprehensive review of the studies of post-secondary programs by Nelson et al. (2023) identified 156 international studies in this field however only two included the perspectives of families and support workers in their titles and as a core focus. In research by Dymond, Meaden & Pickens (2017), semi-structured interviews were conducted with 10 parents and 6 university personnel affiliated with a single public research university. Through analysis, five key themes emerged, focusing on (a) understanding the characteristics and needs of students with ASD, (b) the transition process to university life, (c) the availability of existing services and supports, (d) barriers and challenges faced by students and support providers, and (e) areas identified as needing additional support. This study extends this work by exploring what other themes might emerge when the perspectives of support workers and the facilitator are included. Interestingly, the importance of the role of the facilitator has begun to emerge more recently as being significant to students and in need of further research (Thompson et al., 2021).

The desirable aspects of further learning programs internationally include co-location in tertiary settings and students having come from integrated secondary schools. Exploring the reflections of postsecondary programs is useful for ensuring continued success but it is also crucial to capture a more holistic overview from the perspectives of different stakeholders (Agarwal, et al., 2020). Parent perspectives are especially important as they are the decision-makers in terms of enrolling their young person in a program and helping them navigate through the transition stage (Agarwal et al., 2020, Culnane et al., 2016, Jones & Goble, 2012; Widman & Lopez-Reyna, 2020). This study will contribute to identifying “evidence-based transition practices and policies that are responsive to the particular strengths, needs and challenges of students with ASD” (Test, et al., 2014, p87) in addition to providing a program description for practitioners.

This research project focuses on the perceptions of the pilot post-school program, using a qualitative approach to provide a more nuanced look at the experiences and the potential impact for families, support workers and the facilitator. This study aimed to address a gap in the literature and contribute in this underrepresented area in the research by focusing on these important perspectives and to answer the research question: What are the families, support workers and facilitator’s perspectives of a pilot post-school program for young autistic students with intellectual disability?


We begin with a description of the pilot program, followed by the method and data analysis before presenting the main themes which emerged and providing recommendations for practitioners and future research.



Description of the program

A new day program was piloted in Brisbane, Australia, for young autistic adults with intellectual disability. The post-school program was for 17-25 year-olds to experience life at university. It was based at a campus of a Griffith University where students and these young adults could mingle on the campus grounds. Like the Uni2Beyond and Up the Hill projects, students were not enrolled students but identified as 'Uni students'. Unlike the Uni2Beyond and Up the Hill projects this program did not include students in class with enrolled students. Program goals included enhanced social and communication skills, socialisation, and further learning. The purpose of the day program was to support transition from High School by providing a regular program during their final year at school and beyond, and to create a new option for further learning and work preparation for people with intellectual disability who have limited options available to them.

The program was designed by a care giver who was an Education Designer at the university where the pilot research took place. As an education specialist and the mother of a son with intellectual disability she conceived the program as a way to give additional opportunities to young adults in need. The initial design of the program included developing the structure based on attendance two days per week, 9am to 3pm. It was a fee for service program with NDIS funding paying for an hourly rate. The content and curriculum were developed to include the planning of the delivery of learning business concepts, therapy, current affairs and entertainment news, passion projects (student-led research projects from their own interests), and an exercise program.



The curriculum was designed to be accessible, visual, and engaging and referred to the Universal Design for Learning (UDL) teaching and learning framework that focuses on providing flexible pathways that support all students in mastering learning goals, so everyone can benefit (Rao, Smith & Lowery, 2017). This gave the students an opportunity to learn what their peers were learning in a way that they could participate, progress, and have success.

A Business Studies curriculum was designed in modules with basic concepts from a first-year Bachelor of Business subject. The modules were produced as online easy-read resources. Support workers sat beside their clients and read aloud, or prompted, or created choices with the text - depending on what was needed. After six months each student had also participated in a couple of 'Passion Projects'. These were co-designed plans to develop personal interests with a view to becoming a future work option for them. This was a measure of success for families, although it was only just the trial of the program. Passion projects included: re-designing rail travel, creating a play list and promotional material for a concert, and designing a brochure for holidays to China.

The process for recruitment of the students involved advertising the availability of places and a description of the program via the parent network and snowballing by word of mouth. Parents of the students were asked to contact the facilitator who conducted the initial screening of potential applicants. Six applied and all were deemed suitable to commence in the program. During the consultation to assess the student the facilitator explained the program and had families, and then students, consent to the research component of the pilot. All six of the students were Caucasians living in the local area, within 40 minutes drive. All the students lived at home with their two parents and had a Diagnostic and Statistical Manual -5 (APA, 2022) diagnosis of Autism Spectrum Disorder at level 3. Three were in secondary school and attending the post-school program part time, and the remaining three had graduated from school within the past four years. The graduated students were either attending other programs the rest of the week or supported by individual workers to access the community.

Table 1*Student Demographics and Pseudonyms*

Pseudonym	Age	Gender	Education Level	Ethnicity
James	17	M	High School	Australian
Rico	21	M	High School	Australian
Ronan	18	M	Still in High School	Australian
Matt	17	M	Still in High School	Australian
Evan	18	M	High School	Australian
Sam	20	M	High School	Australian

Several strategies were incorporated into the pilot program to support success for the young adult learners. These revolved around sensory needs, managing anxiety, and communication. A common experience for autistic people is sensory seeking or sensory avoiding for regulating their bodies with sensory processing captured in diagnostic criteria (APA, 2022). Parents were asked about sensory preferences for their young adult prior to enrollment and the students were carefully observed and provided with different options to see what offered the best assistance to them. In a 2022 study of the sensory experiences of 49 autistic adults, MacLennon et al. describe the prevalence of hyper-, hypo-, and sensory-seeking reactions to input.

A combination of hyperreactivity and sensory-seeking was the most commonly reported input by the adults and this was moderated and managed in a variety of ways. The post school program had a ‘chill out room’ created in an adjoining space with a comfortable sofa, mood lighting, and fidget toys to help the students manage sensory input. An additional space was altered to be a ‘de-sensitising space’ where lighting was off, a coloured bubble fountain created a soothing hum and bean bags and weighted blankets were available. Students could move to those spaces any time they wanted or needed. Support workers were also trained to monitor the students and so that when they saw signs that the individual was becoming dysregulated, were encouraged them to move to other rooms to support them to feel better again. Anxiety is common for autistic people (Kent & Simonoff, 2017) and was managed for some students via medication, and others via predictable routines and choices for all activities. Unlike school, there was no demands to adhere to group activities. Visual schedules were designed into the program to support basic routines and choices.


A fundamental principle underpinning the program was that each student was competent and capable of learning in the right circumstances. The support workers played a key role in being a communication partner for the students. They were trained to model the use of augmented communication tools, provide opportunities for choice, and together with the facilitator, modify activities to allow more participation. The facilitator was an early childhood trained teacher who had an autistic close family member with intellectual disability. She had spent some time in her previous teaching role as the Disability Support Coordinator at her school.

A Typical Day

A typical day began with a story chosen by a student from a collection of picture books followed by individual identification of where they located their level of regulation and their emotional state at that time on a poster using Zones of Regulation (<https://zonesofregulation.com/>). The next 30 minutes was a learning activity, sometimes individual, sometimes group.

A favourite shared activity was the card game Uno. The game was used to help the students connect with each other. Following that session they would go to the dining hall for morning tea. They would often 'stim' at this time – rock back and forth, listen to music, spin around or pace.

Therapies (music, art or exercise) followed morning tea. These were delivered by external experts who came to the room or a designated space to run the activity. Next came lunch at the dining hall again, or one day a week in the campus cafe. They ate inside at booths or outside at cafe tables with university students and staff. After lunch, they went to a lecture theatre for a current affairs and entertainment quiz on the big screen. Returning to the room, the students had 30 minutes of 'down time' before starting their sharing stories.



In early discussions with families, they all hoped that expressive communication would improve so their son could share about their day at university. Building on this request, the Facilitator initiated a sharing time at the end of every day. The students presented their sharing story on the big screen to the group before packing up, tidying and saying goodbye for the day. The stories went home with them to be shared with their families. These simple narratives are like Social Stories, which were first developed in the 1990s to help autistic children understand social conventions and experiences (Smith, 2017).

Next, we present the method used to collect and analyze the perception of family, support workers and the facilitator of this day program and then the results are explored.

Method

Design

This study was qualitative in its approach to explore the perceptions of the families, facilitator, and support workers of the pilot day program. Semi structured interviews were used to explore the main themes which emerged from these perspectives.

Participants

Six mothers and six fathers, three adult siblings, seven support workers and one program facilitator were involved in the research. Research participants (siblings, parents/caregivers, and support workers) gave informed written consent in keeping with ethics approval (2021/924). As a result, 23 people who were purposively recruited provided qualitative data. The table below outlines their demographics.

Table 2*Participant Demographics*

Participants and their relationship to students	Gender	Age range	Education Level	Ethnicity
James				
Facilitator	F	40-50	Bachelor degree	Australian
mother	F	40-50	Diploma	Australian
father	M	40-50	Diploma	Australian
sister	F	20-30	High School	Australian
support worker	M	30-40	Vocational college certificate	Australian
Rico				
mother	F	40-50	Diploma	British Australian
father	M	40-50	Bachelor degree	British Australian
Ronan				
mother	F	40-50	Post-graduate	Irish Australian
father	M	40-50	Diploma	Australian
support worker 1*	F	40-50	Vocational college certificate	Australian
support worker 2	M	20-30	High School	Australian
Support worker 3	F	30-40	High school	Australian
Matt				
mother	F	40-50	Diploma	Australian
father	M	40-50	Bachelor degree	Australian
support worker	M	30-40	High School	Brazilian
Evan				
mother	F	40-50	High School	Australian
father	M	40-50	High School	Australian
sister	F	20-30	Vocational college certificate	Australian
support worker	F	20-30	High School	Australian
Sam				
mother	F	40-50	Diploma	Australian
father	M	40-50	Vocational college certificate	Australian
sister	F	20-30	High School	Australian
support worker	F	20-30	Vocational College certificate	Italian

*Note Ronan had a different support worker each of the two days, and one was replaced part way through the pilot. All three were interviewed for the research project.

The students communicated in different ways, sometimes this varied for an individual by situation and by day. None of the students showed communication at the level of their same-aged peers. Most used augmented communication tools such as picture to speech apps like Proloquo2Go and devices with software like NOVA Chat. James used speech, including repeated phrases, and some writing.

Measures

This paper drew on semi-structured interview data. A semi-structured interview research protocol was developed with similar questions asked of families, the facilitator, and support workers. These included questions about the young autistic person, expectations, experiences in the post-school program, motivations for joining the program, any benefits or successes received, challenges, suggestions, and other relevant input.

Procedure

One on one semi-structured tele-interviews were conducted by a researcher on Microsoft Teams. A schedule of interviews was arranged with participants for 30 minute meetings. The interviews were recorded and automatically transcribed by Microsoft in the Stream application. The automated transcriptions were checked and reviewed by another researcher to ensure verbatim transcriptions of the interviews were generated. These interviews were conducted on the students' parents, siblings, support workers and the facilitator halfway through the six month trial. A total of 23 interviews were completed.

Analysis of data

Thematic data analysis was conducted by one researcher and cross checked by the others on the interview transcriptions using Braun and Clarke's (2006) guidelines. This qualitative methodology uses inductive reasoning to privilege participant perspectives in the analysis of in-depth information collected from the parents, family, support workers and facilitator of the young autistic adults with intellectual disability enrolled in the post-school program. Firstly, the transcriptions were reviewed to allow for the researcher to become deeply engaged with the interviewees' perceptions and key focus points. Then initial codes were identified from the transcripts using Leximancer with sub-themes and themes identified. Notably these codes and themes were data driven and emergent rather than priori or relating directly to the interview questions.

Finally, the themes were then reviewed. Key themes from these constructs are reported with supporting statements. The themes were: participation, friendships, program experiences, communication, and the role of a carer. These themes were cross checked by one of the other researchers to ensure consistency and accuracy.

Data Analysis

The main themes which emerged from the qualitative data were: participation, friendships, program experiences, communication, the role of a carer. These are presented with supporting evidence from the participants in the interviews.

Participation

In the interviews, James' father was pleased to share that his son was "participating and encouraging the other kids as well to get involved". This was observed throughout the pilot, with James being described by the facilitator as 'the glue' between the students. His father went on to say, "it's great for socially, for him to be able to, you know, feel comfortable enough to encourage people to have a go or, you know, to participate and join in". Two of the students, Rico and Evan, were expected by parents to struggle due to negative past experiences, so their parents' hope was that they would make it through a whole day and show some enjoyment. Evan's support worker, a young female studying Behavioural Science, described how often Evan asked to go home: "At the start it was like every half an hour. And now sometimes he won't ask for the full day until he's ready and then he's like can we go home please?... So, he's actually gotten better at staying for longer, but then recognising and articulating that". After six months, both young adults were still involved in the program and were indicating they were happy on a regular basis. Their participation in activities was the same as the other young adults and they were staying all day, or most of it.

Matt's support worker, a teacher trained in Brazil, said "He socialises better now...". At the beginning, my job with him was doing exercise and doing activities and being active but now being part of something, you know, it's not just me and him - that changes everything". His father added "when they're at the uni they go and buy lunch and there's other people, the students, coming and going. There are things happening and he gets to have a feeling that he's participating in something which is age appropriate".

Sam's support worker, a young Italian female with experience in other day programs, said she "saw a lot of improvements on the way he socialises [and] he has been learning more sentences. He learned how to play Uno, you know he does exercises [now]. I saw him doing many things that he never done (sic) before". She also described how she was more relaxed because he was in a safe environment and she didn't have to worry about him running away, something he often did out in the community.

Ronan was always on his feet. He liked to stand at his desk and stay at the edges of the room and not be touched. His support worker, a young man of a similar age, said: "He sort of hangs back and stuff, and watches them, and to see him get more and more involved every week. I think it's having that positive effect on him socially... so there's that peer pressure, but it's that good peer pressure".

Findings regarding the delivery of the pilot program suggest it had its challenges. At first Covid-19 campus closures caused breaks in service delivery, a local flooding event contributed to time not on campus, and early in the pilot the program moved from a temporary space to permanent rooms. These all had an impact on the students. The facilitator noted "Unfortunately, when we had to change our rooms, that sort of did throw a spanner into the works of the program. James, Ronan, Matt and Sam coped quite well with the change. Rico seemed to be okay, but he is having a few problems at the moment. Evan really struggled with the change in rooms and is still struggling with it".

Some of the impacts were positive though. During some of the campus closures the support workers and the students met up socially at parks, beaches and other outdoor activities. This helped build friendships so when they returned to campus they were excited about seeing each other again.

Friendships

Friendship was described by mothers in this study in four of the six interviews in relation to reducing isolation, forming friendships, and gaining a sense of belonging. For Ronan, ‘the funny young men’ he was grouped with turned into friends after a few weeks, as reported by his mother who had read it in his daily stories. His mother said, “This is a boy who, you know, described many years ago about how his main aim was to have a friend”. In Week 9 he shared via typing in a daily story: “Today I liked the crazy, creative boys”. Two months later, after a summer break, Ronan again shared via typing “It was good to see my friends again, and [the facilitator]. I enjoyed Specialise [the exercise program] and the Frozen quiz”.

Rico’s parents valued friendships very highly for their anxious son: “Well, it gives him, you know, friendships that he doesn’t have”, “He’s sort of lacking that friendship since he left school, so it’s a nice place to go and make friends and do different things” (Rico’s mother). The post-school program had changed the isolation their sons had experienced and the anxiety that crippled their sons’ attempts at coping with change after school. “He talked about past friends from school, but he hadn’t been able to make any friendships out of school” (Evan’s mother).

The facilitator confirmed that friendships were developing well, “the boys have a real friendship base now and they go and do things on the holidays as well. So, they’re not just interacting in the program, they interact outside the program as well. So, they really have made some friendship groups, which is really nice.” Relationships also developed with the mothers through a ‘Whats App’ group. It was created as an informal way of organising meet-ups between the support workers and students during campus closures.

Over time it became a platform to ask questions about funding reviews, rites of passage – such as turning 18 and the associated access to support, and fundraising initiatives.

Communication

The support workers provided help in everyday activities and with communication. As previous ‘community support’ workers most of them had not considered communication assistance beyond supporting basic requests prior to their involvement in the post-school program. James used speech much of the time, but his support worker still benefited from learning about communication to support him. He stated that the first course in the training package showed him "a lot more ways to communicate than I thought". As the five courses progressed, he said he ‘learned how to improve communication’ and ‘to be more patient’ with his client. Finally, he felt that participation had helped him ‘believe in himself’ as a communication assistant. The facilitator also believed she had developed new skills in the program, “I have learnt how to use augmented communications [tools and strategies]. So, I've learned how to communicate with Ronan, Matt and Sam with their communication devices, so that has been a real improvement for me with my education”. Story sharing at the end of every day contributed to some improvements in communication, reported in parent and support worker interviews, he “talks about [the program]. I think that’s a real positive change” (James’ father), and “a real improvement in his expressive language”, (James’ mother). His sister said: “He’ll come home and he’ll just tell mum about different things that he's doing, and we're just like amazed like our brains are just ‘going’, because we're just like - he wouldn't come up to us ever and talk about something that”.


Sam’s father said: “He's better at communicating what he wants instead of getting upset”, and “His communication across the board, in my opinion, is sort of improved”. This was reinforced with a group communication session each week with a Speech Language Pathologist in ‘aided language stimulation and AAC modelling’ (Rourke, 2019, p. 78), a more naturalistic teaching strategy than traditional therapy sessions.

Program Experiences

The unique structure of the program was discussed in most interviews. Mothers described the other options available and how they preferred the post school program because of the further learning and routine for their adult child. Fathers described the need for something to do, a purpose in life -that the program offered. The support workers described the uniqueness of the program and how it was a positive environment with fun and a relaxed atmosphere. The facilitator discussed the inclusion aspect at the campus and said, “I think it's very healthy for the wider community to be able to see them and meet them and interact with them”.

In interviews with fathers, they talked more about challenges more than mothers did. All of the fathers described the challenge of finding a suitable purpose for their sons: “We were struggling to find what to do”, “not just have him involved in the same day activities over and over or in unsuitable day facilities that wouldn't really benefit him much” (Ronan's father), “It's very hard to fill the week with things that are purposeful” (James' father). And subsequently, the relief of having an option that was rewarding: We “feel better knowing he is doing something, not just spending his time just existing” (Evan's father), “It's hard to find good programs. It [the post-school program] seemed to be more than a childminding program. And they want to achieve things” (Matt's father).

The mothers agreed that the post-school program was meeting their son's needs for a purposeful experience. They described the other options, including day programs as “It felt like we were hiding him away” (Ronan's mother), and social and community participation with a support worker as “walking around shopping centres” (Evan's mother). James' mother said, “I know what I didn't want him doing - I didn't want him in day programs that weren't able to focus on those learning experiences”.



Half of the parents commented on the importance of learning in their interviews. They had concerns that regular day programs did not support meaningful learning opportunities and were “more like childminding” (Ronan’s father), and they felt their son had delayed learning so “should have the opportunity to continue learning beyond school” (James’ mother) and “do what other 18, 19, year old school leavers would do. Which is either go out to the workplace ...or further learning - further education” (Ronan’s mother).

Families explained how their sons enjoyed being around people their own age and how their son’s happiness and enjoyment of their interests had an impact on family life. The structure of the post-school program in a shared space with a small group of students made the young adults comfortable, and families reported when “he is happy or more comfortable, everybody obviously becomes a little bit more comfortable” (James’ father), and the benefits impacted the family’s well-being “for us too, because he always comes home in a good mood” (Sam’s father).

The facilitator focused on the choice and control the students had within the program. They could opt out of activities, or deal with management of their sensory needs in the way that suited them, “You know, we have chill out spaces here where they can go when they are overwhelmed, or if they don't like it. So, the whole idea behind this program is not only giving them access to the community, giving them access to people their own age, but giving them choice”.

In regard to the program experience, all the support workers described the post school program as unique, relaxed, fun and a positive experience. Matt’s support worker, a lady who had worked in special education for 15 years, said: “I think it's a great transition from school, so they just start coming out and socialising, learning some new things, mainly the socialising aspect of it, especially for young autistic adults coming out of school”.

Role of the Carer

Ten of the twelve parent interviews described how their role as a carer impacted them and their families. They described the caring role in terms of how difficult, busy, tiring, or worrying it was: “We were both diagnosed with depression. Anxiety was high” (Ronan’s father), and “we didn’t really do like family holidays... He has like a lot of anxiety” (Evan’s sister). This post-school program represented security and stability to the parents, “It’s, for me, security.....I’m confident that what he is getting - it might be difficult for him to cope with - but is good for him, whereas I can’t say that of anything else I tried last year” (Evan’s mother).

All the parents acknowledged that mothers did most of the organising and planning for their student. This was very apparent when they talked about transition planning from school to the adult world. Transition represented a challenge for parents. One father said: “She is a bit more switched on than I am with all this anyway” (James’ father), “I think she deals more with it than I, actually” (Rico’s father), “I mean she does the bulk of the NDIS stuff” (Sam’s father). Mothers were organising support workers and activities for their adult children, and it was a difficult job. The facilitator confirmed her understanding of what the families had experienced, “I know Rico’s mum, when we when she came to look at the program and look at the university and we walked around, she had a few tears. She told me about what he’d gone through in the past and how he just never fit in anywhere... and she didn’t hold a lot of hope”.



DISCUSSION

Now we present a discussion of the results which emerged from the reflections of the families, support workers and facilitator, in light of the literature. Findings relating to the satisfaction with the program and in particular, the supportive environment that was established, are consistent with what is known to be ‘good practice approaches’. For instance, the attention the facilitator paid to students’ sensory needs and management. According to Rourke (2019), sensory habits and favourites can be a form of stabilization and orient attention and structure capacities. The intention for interaction can work to address sensory issues that impact social inclusion and this program supports this finding.

The impacts from this program were multidimensional and included improvements in behaviour, relationships, enjoyment in the program and having a purposeful experience. Carer impacts were of considerable consequence with even some indications the program led to wider family benefits and stability. Some parents indicated that they had significant concerns about their student’s post-school options and their abilities to adapt. Preparing the children for the ‘outside world’ seems to be a more explicit and conscious aim for fathers when interacting with their child with disability (Vatne, et al. 2022). Research has shown that parenting a child with disability results in different experiences for mothers and fathers, including the expression and regulation of sadness (Vatne, et al., 2022), elevated levels of parental stress and elevated depressive symptoms (Paynter, et al. 2018). This appears to be reflected in interviews with mothers and fathers in this study. The program had alleviated those concerns bringing a sense of satisfaction and security for the whole family.

Teachers also feel they need extra training to teach the child who works with an iPad to communicate (Dada, 2019) so the support workers and facilitator did communication training at the beginning of this project and, as a result, were immediately able to support the students to express themselves in a way that reduced behaviours of concern and increased choice and control for the students. As Test et al (2014) note, difficulty coping with change is part of autism, and sometimes small changes in routines and environment can be a challenge. Indeed, change was a challenge for the students in the program but the program had the environment and the strategies to deal with that. Change was also a challenge for families through transition from school to the adult world.

One characteristic of autism is difficulty with relationships (APA, 2022) which can lead to social isolation for autistic adults. Mothers in Strnadová and Evans (2013) research expressed concerns about the development of friendship skills they perceived as crucial to social inclusion and wellbeing (p. 74). Similar findings were reported in this study where mothers expressed the positive impact from their students's new sense of belonging and budding friendships. Indeed, these results regarding the positive impacts of 'finding friends' and the broader social benefits and ripple effects that emanate from this are in themselves indicative of the program's utility.

Other psychosocial benefits were identified in the program too. Fathers of younger autistic children find public judgement difficult because their child does not display obvious signs of disability (Paynter, et al., 2018). However, these young adults appear obviously disabled and parental stress may instead arise from public observations, like staring. Despite this, fathers noted the positive impact of their son's sense of enjoyment in the program on the family. Fathers also feel much worry and fear for their children's wellbeing and future (Vatne et al. 2022). However, the program had given their sons some purpose and the fathers subsequently felt the relief of having a rewarding post-school option. Further research is needed to explore and identify how these options develop, and moreover, how father/son and broader family dynamics may evolve as a result.

Perhaps the ultimate indicator of the program's success was the continued participation by all the students. Expectations of one or more parent is a significant predictor of postsecondary education participation for autistic students (Test, et al., 2014, p. 83). Indeed, parents with low expectations for success did see their sons struggle more to settle. However, they had previous experiences of failed programs, so this attitude is not surprising, nor likely the cause of the slow transition.

Despite the benefits described from such programs, it has already been noted, that these initiatives remain in their infancy in the Australian context and are yet to be clearly and sustainably funded. Whether viewed from a post-secondary schooling options/employment pathways lens, or from a social inclusion, family support lens perspective, it is clear these programs are needed and highly valued by students and their families. Further research is needed to demonstrate the return on the (relatively small) investments required and identify the most sustainable model to continue delivering these programs.

Recommendations for Practitioners

Learnings from this program underscore the need to be mindful first and foremost to establish a welcoming, safe environment that considers and supports the sensory management and individual needs of students. Program participation is key and providing the required mix of activities and opportunities to regularly check-in, respond and adapt as required, according to the results of this program, were not only valued but underscored high levels of program participation. The attention given to opportunities to develop friendships within the cohort also suggest there is a need to maximise such opportunities for connection.

This includes benefits for peer learning, great interaction, communication and wellbeing more broadly. Underpinning such adaptability and responsiveness was the relationships established with families and the attention given to eliciting feedback and privileging of students, as a routine continuous improvement activity. However, big changes to the environment should be avoided.

Limitations

This study occurred in one geographic area with a small group of families. It would be helpful to measure the progress of the program over more time and the impact it has on students. Future research with comparison groups would be of value to ascertaining the direct impacts of the program as well as component analysis of potentially effective elements (e.g., therapy vs. business classes vs. social contact).

Conclusion

The perceptions of the family and support workers in this program indicate students had benefitted from the post-school program and reported that it created stability and security for the family. It was noted that, for some students, it took many weeks to feel settled despite the modified environment and program to meet their needs. It was reported that they enjoyed their developing friendships and this had a positive effect on family well-being. Modified learning materials provided them with opportunities to learn what their peers were studying. The campus experience was an opportunity for inclusion that was desired by families.

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