



WESTERN SYDNEY
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THROWN OUT INTO THE WORLD:

TRANSITION TO POST SCHOOLING
FOR AUTISTIC YOUNG PEOPLE

RESEARCH CONDUCTED BY WESTERN SYDNEY UNIVERSITY
FOR NORTHCOTT DISABILITY SERVICES

Dr Caroline Mills, Dr Nicole Sharp, Dr Zoi Triandafilidis and Professor Danielle Tracey


Northcott

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Western Sydney University 2022

A NOTE ABOUT LANGUAGE:

This report has adopted identity first language (i.e., autistic young people) instead of person first language (i.e., young people with autism) when referring to autistic people. This is reflective of feedback from the autistic members of the advisory group for this research project.



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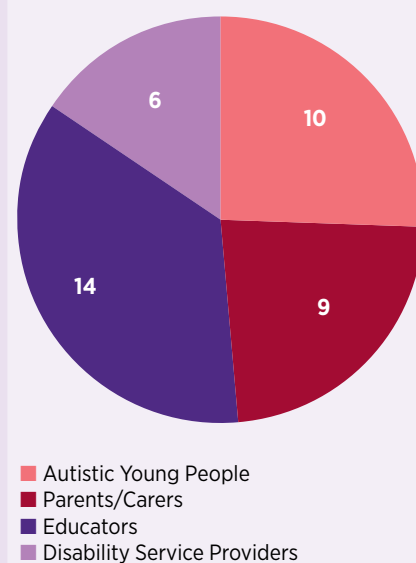


EXECUTIVE SUMMARY

This study represents a co-produced qualitative investigation about the experiences of autistic young people in their transition from high school to post schooling. The study's core aim was to understand the perspectives and experiences of four groups of key stakeholders (autistic young people, parent/carers, educators and disability employment service providers) around the transition of autistic young people from school to post-school education and employment options. More specifically, it seeks to understand this experience when there is no access to NDIS funding. In all, the study provides a voice for the current concerns of stakeholders to provide recommendations for initiatives to address the identified issues.

This study adopted a qualitative approach with 39 people participating in semi-structured interviews describing their experiences. Ten autistic young people were interviewed at two and three time points (24 interviews in total) in order to provide a viewpoint for how their experiences change over time. Nine parent/carers, 14 educators and 6 disability service providers were interviewed at one time point. Interviews were recorded and transcribed verbatim for analysis. Analysis was conducted using a reflective thematic analysis approach.

FIGURE 1: Breakdown of 39 people who were interviewed



NINE FINDINGS ABOUT POST SCHOOL TRANSITION:

1 The transition to post schooling for autistic young people is fraught	All stakeholder groups reported that significant challenges were experienced by autistic young people when transitioning from school.
2 Every autistic young person's experience is different	There isn't one universal experience for autistic young people. Similarly, their strengths, challenges, interests, and goals vary. The transition process must recognise individuality.
3 A deficit view prevails where the autistic young person is viewed as the problem to be fixed	Participants largely focused on how young people should be supported to overcome their challenges so they would be fit for post schooling. Less was said about how the post schooling environments should be designed for all.
4 Young people want a chance to prove themselves	Autistic young people want employers to give them a chance to prove themselves.
5 There is limited support for autistic young people and their families	Autistic young people can lack support, particularly when it comes to transitioning from school to post-school.
6 The complicated and limited access to appropriate funding locks out autistic young people in need.	The process of accessing appropriate funding (including NDIS funding and other types) is difficult and the eligibility criteria is restricted, with some people missing out and falling through the gaps.
7 There is a 'siloed' approach to supporting the transition which results in gaps	Participants often blamed failures on the other stakeholders in the ecosystem. This resulted in gaps in service provision. It remained unclear who was 'driving' the process.
8 Inequity arises with inconsistency of supports: a good outcome depended on "luck" rather than a good system	Widespread inconsistency of supports was reported from the stakeholder groups. A good outcome came from being 'lucky' with parental capacity, NDIS Local Area Coordinators, teachers, employers, TAFE or university. Such systematic inconsistencies breed inequities where those most vulnerable are further disadvantaged.
9 COVID-19 exacerbated difficulties	The COVID-19 pandemic and lockdowns resulted in diminished support and poor motivation and mental health for autistic young people.

SEVEN RECOMMENDATIONS TO OPTIMISE POST SCHOOL TRANSITION:

1 Transition planning needs to start early	Transition planning needs to start early as an ongoing process throughout high school. Collaboration and clear role delineation is required with a potential for adopting a key worker model.
2 Improve awareness and capacity of workplaces. TAFE and Universities	Much of the findings reinforced a deficit model. There is a need to strengthen universal design in schools, tertiary education environments and workplaces. Stigma and discrimination about neurodivergence should be challenged.
3 Adopt an individualised approach, driven by an autistic young person's passions	Strengths and interests of autistic young people should be recognised as something which can be developed and lead to a career. Young people need support to take a leading role in planning for their future.
4 Expand access to intensive school leaver employment supports like School Leaver Employment Supports (SLES)	Re-assess the Disability Employment Service (DES) model and expand access to more intensive employment supports for autistic young people, especially when they are unable to access the NDIS or other funding options.
5 Support the mental health of young people and parents	The mental health of young people and parents should be prioritised. Not only is positive mental health an important outcome in its own right, but it is also foundational to navigating a successful transition.
6 More resources and access to work experience is needed in schools to support young people to prepare for transition	More resources are needed to support transition – including Support Teachers Transition (STT), allied health professionals in schools and tailored services for those not eligible for NDIS. Work experience in school is essential for success.
7 Raise their voices	Bring the voice of lived experience into individual planning and systemic processes to optimise their application and success.



**WHAT IS THE
PROBLEM?**

DISABILITY AND LIMITED PARTICIPATION

Australians with disability experience “deep and persistent social exclusion” (Australian Institute of Health and Welfare, 2017, p. 48) more than twice that of the national prevalence. For instance, compared to those without disability, adults with disabilities in Australia experience:

- More than double the unemployment rate;
- Twice the rate of financial stress; and
- Almost half the likelihood of completing Year 3w12 by the age of 20.

Furthermore, people with disability regularly experience discrimination impacting on their participation, with 1 in 6 experiencing disability discrimination in the last year, and 44% of complaints to the Australian Human Rights Commission being about disability discrimination (Australian Institute of Health and Welfare, 2022).

AUTISM, EDUCATION, AND WORK

Autism is a lifelong developmental disorder which impacts on how a person communicates and relates to other people. Autism is characterised by persistent deficits in social communication, interaction, and restricted or repetitive behaviours and interests (American Psychiatric Association, 2013). An estimated 205,200 Australians were diagnosed with autism in 2018 (Australian Bureau of Statistics, 2018), and around one in 100 children have autism worldwide (Zeidan et al., 2022). Many children experience delays in receiving an autism diagnosis and miss out on the benefits of earlier and more intensive treatment (Pasco, 2018).

Over 90% of autistic young people will experience restrictions in education, and around 40% will attend a special class or special school (Australian Bureau of Statistics, 2018).

Common experiences include difficulties with social interactions and relationships, learning, and communication (Australian Bureau of Statistics, 2018). Autistic people are also less likely than others to go on to earn tertiary qualifications, with only 8.1% having a bachelor's degree, compared to 31.2% of people without disability (Australian Bureau of Statistics, 2018).

Employment participation rates for autistic adults are at 38%, compared with 84.1% of working age people without disability, and 53.4% of all working age people with disability (Australian Bureau of Statistics, 2018). These statistics highlight the need to improve outcomes for autistic young people in education and work settings.

Despite these alarming inequities, autistic young people exhibit a range of strengths which can facilitate a positive contribution to a workplace. These include a high intellectual capacity for some autistic young people (Emberti et al., 2018); strengths with the use of technology (Bailey et al., 2022); visual processing (Kunda & Goel, 2011), and attention to detail (Happé & Frith, 2006). They may also exhibit strengths and interests which may contribute to the job role (Baker-Ericzen et al., 2022). Autism-specific employment programs such as the Dandelion Project (Hedley et al., 2017) have shown positive benefits to employing autistic people, provided supports are in place such as supportive work relationships for autistic workers (Hayward et al., 2019); employment support services which match a person's needs (Baker-Ericzen et al., 2022) and accommodations within the physical and sensory environment in the workplace (Hayward et al., 2019).

Work experience comprises work placements or internships with employers and are linked to positive employment outcomes for people with disabilities (Weld-Blundell et al., 2021). A systematic review by Weld-Blundell et al., (2021) described that successful employment outcomes could be achieved following a range of employment initiatives for people

with disability including intensive job skills training both on and off the job, combined with an internship undertaken in the final year of high school. Similarly, a study by Beyer et al., (2016) described the 'Real Opportunities' work experience/job placement program for people with disability. The program included job coaching support comprising a process of 'job matching' to a young person's skills and interests. The program engaged transition key workers to support families through transition, built on independence skills and included targeted social integration with non-disabled peers (Beyer et al., 2016). These studies illustrate that successful work experience participation may comprise a multi-element approach with a number of initiatives leading to success. Clarity is needed around what defines a 'successful employment outcome' with studies offering varying definitions, making measurement difficult (Weld-Blundell et al., 2021). Further studies are needed to consider how supported work experience may lead to paid employment success.

In seeking to address the inequities evident in participation in work and education, the transition from school to post-school has been identified as a period where autistic young people do not receive adequate support and, regrettably, understanding how to improve support remains a gap in the research literature (Hoffman & Kirby et al., 2022; Schall et al., 2014).

CONCERNS ABOUT TRANSITION SUPPORTS FOR AUTISTIC YOUNG PEOPLE

Northcott is a specialist service provider for people with disability, providing a wide range of supports and services including vocational and life skills programs to support the transition from high school into employment, further training and other services (Northcott, n.d.). Northcott's experience raises the concern that since the introduction of the National Disability Insurance Scheme (NDIS), funding supports for

young people with disabilities transitioning out of school have changed, leaving potential gaps in post school/employment support funding for some young autistic people.

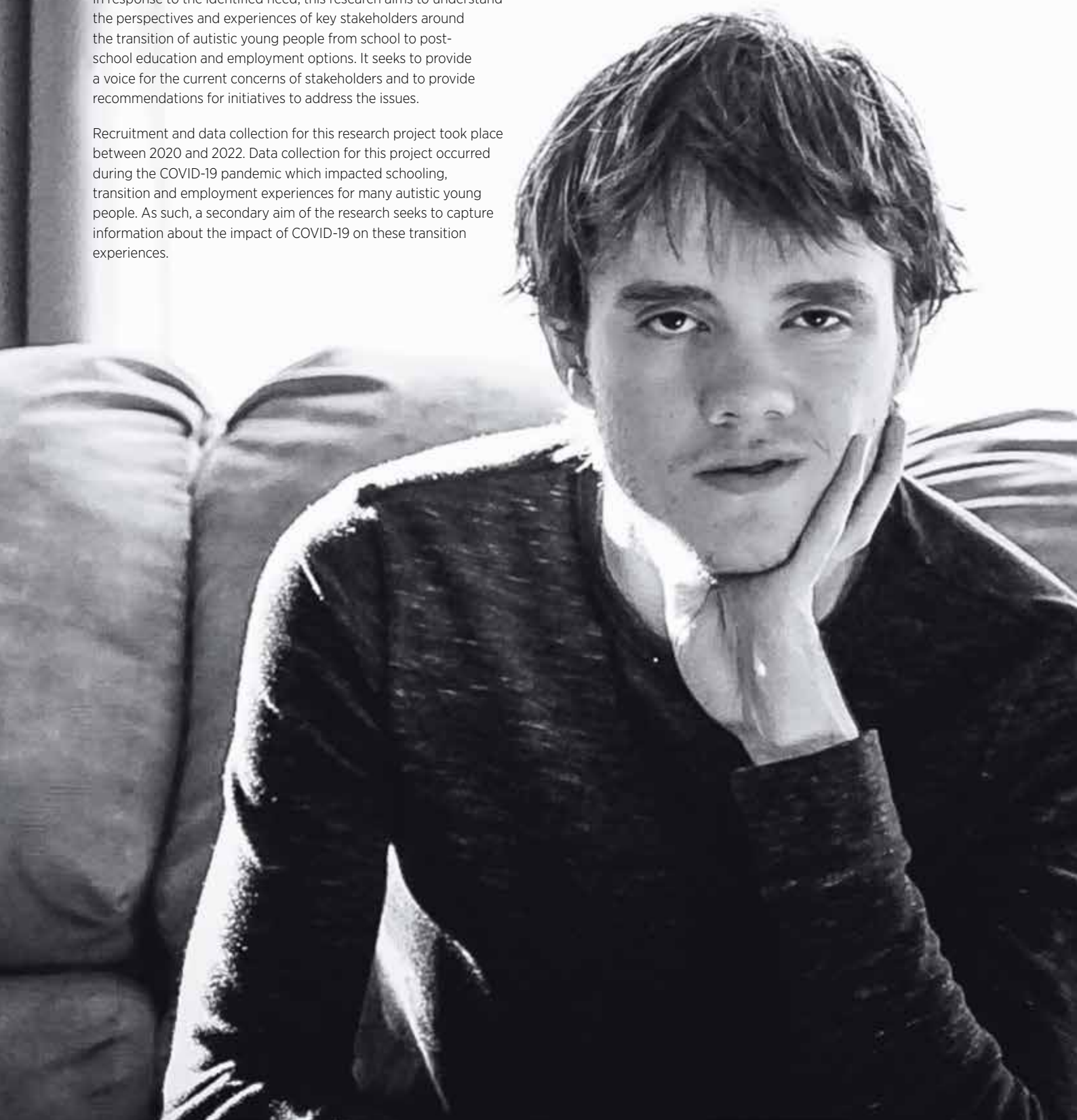
Prior to the introduction of the NDIS, many young people with disabilities were eligible upon leaving high school for New South Wales (NSW) Government Department of Family and Community Services (FACS) support under the two-year Transition to Work (TTW) program. Some individuals are now eligible under the NDIS for School Leavers Employment Support (SLES) or 'finding and keeping a job' support. Individuals who have been deemed not eligible for, or have not tested their eligibility for, individualised NDIS funding, cannot access either SLES or 'finding and keeping a job' support. They may be able to access support from Disability Employment Services (DES). DES providers are funded by the Australian Government Department of Social Services to help people with disability, injury or health condition to prepare for, find and keep a job. This represents a shift in the available supports and associated eligibility which may result in an under-served group of young people in need. In 2022, the Australian Federal Government identified the need for improvements to the quality of employment services for people living with disability, reporting that many DES providers were failing to provide adequate support to people with disability (Ministers for the Department of Social Services).

Considering the significant ongoing changes taking place in relation to support for high school leavers with disability in NSW, it is timely to explore whether current transition services are meeting the needs of autistic school leavers and what the perceived enablers or barriers are to successful post-school life for this group. Northcott highlighted the need to understand what support autistic young people ineligible for the NDIS are receiving in the transition post-school process, if any, and any unmet support needs.

RESEARCH AIMS

In response to the identified need, this research aims to understand the perspectives and experiences of key stakeholders around the transition of autistic young people from school to post-school education and employment options. It seeks to provide a voice for the current concerns of stakeholders and to provide recommendations for initiatives to address the issues.

Recruitment and data collection for this research project took place between 2020 and 2022. Data collection for this project occurred during the COVID-19 pandemic which impacted schooling, transition and employment experiences for many autistic young people. As such, a secondary aim of the research seeks to capture information about the impact of COVID-19 on these transition experiences.



A man with a mustache and goatee, wearing a red tank top, is smiling and holding a tablet. The background is a blurred outdoor scene with trees and a car. The text "HOW DID WE INVESTIGATE THE PROBLEM?" is overlaid in large white letters.

**HOW DID WE
INVESTIGATE
THE PROBLEM?**

QUALITATIVE DESIGN

The project adopted a qualitative design to understand the perspectives of key stakeholders with experience around the phenomenon of autistic young people transitioning from school. Qualitative research allows the development of an in-depth understanding of the perspectives of people with experience around a phenomenon of interest, and their interpretation of these experiences within unique contexts and settings (Creswell & Creswell, 2018).

Semi-structured individual interviews in person or on Zoom were conducted with 39 stakeholders (10 autistic young people, 9 parents/carers, 14 educators, 6 disability and employment service providers). The autistic young people were interviewed two or three times, at 6–9-month intervals, to understand their experiences over time. All other participants were interviewed at one time point only. Reflective thematic analysis (Braun & Clarke, 2019; 2020) was used to systematically identify and organise patterns of meaning embedded within the qualitative data. Ethical approval to conduct the research was obtained from the Western Sydney University Human Research Ethics Committee and the NSW Education State Education Research Approvals Procedure.

CO-PRODUCTION WITH ADVISORY GROUP

Co-production of research which recognises people with disability as not only participants, but as co-creators of knowledge, represents best practice in disability research. Co-production is a process of collaboration and collective decision-making that brings together people with disability, their families and carers, service providers and researchers (Strnadová et al., 2020). In this study, the research purpose, design, and processes were co-produced with an advisory group of autistic young people and service providers with significant experience working with autistic young people. The advisory group comprised two service providers from Northcott and four autistic young people, three young men and one young woman. The young people were reimbursed for their time and expertise.

PARTICIPANTS

There were 39 participants in the research, representing four key groups of participants. .

GROUP 1: AUTISTIC SCHOOL LEAVERS

A total of 24 interviews were conducted with ten autistic young people. Four participants were interviewed at three timepoints with the remaining six participants interviewed at two timepoints.

FIGURE 2: Timing of interviews with autistic young people

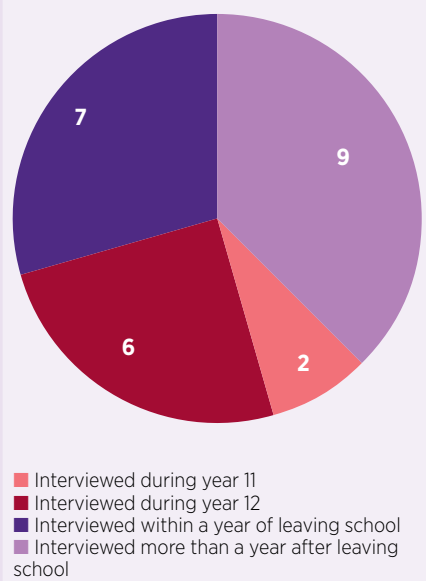


FIGURE 3: Autistic young peoples' gender

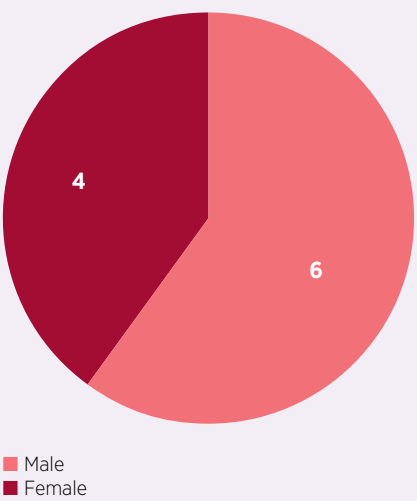
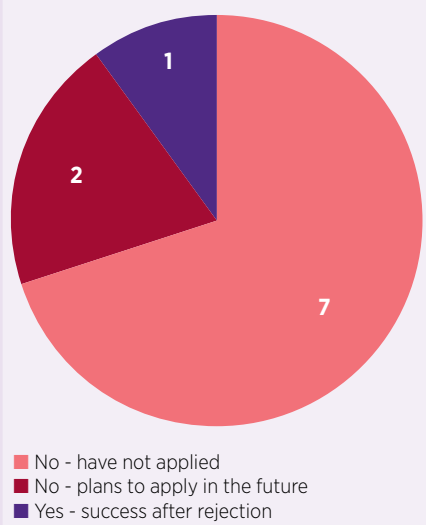


FIGURE 4: NDIS access for autistic young people



GROUP 2: PARENTS/CARERS OF
AUTISTIC YOUNG PEOPLE

FIGURE 5: Relationship to young person

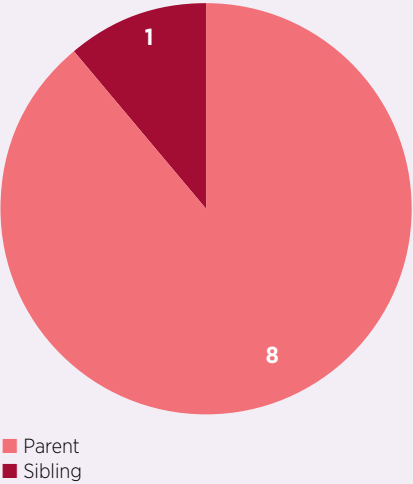


FIGURE 6: Young persons' gender

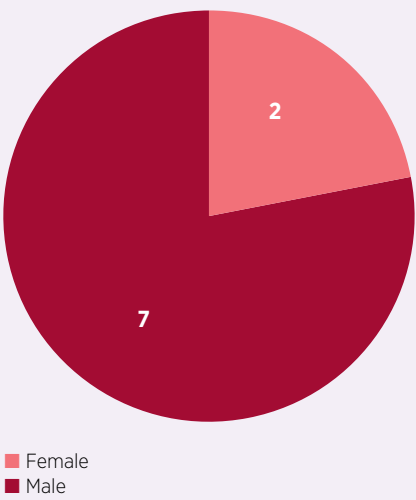
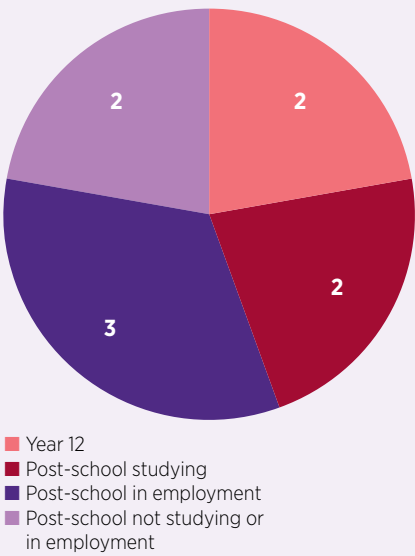


FIGURE 7: Transition stage for young people of parent/carers



GROUP 3: EDUCATORS OF AUTISTIC YOUNG PEOPLE

FIGURE 8: Professional role of educator

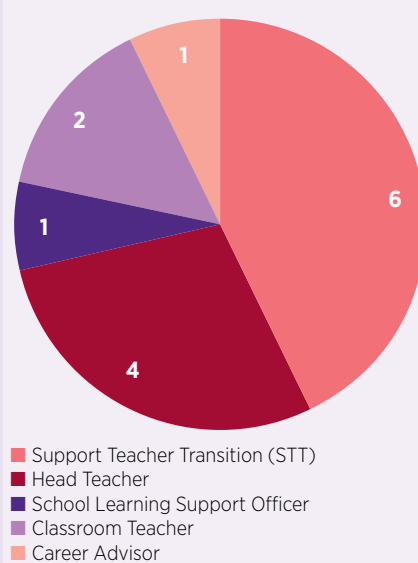


FIGURE 9: Student year level taught

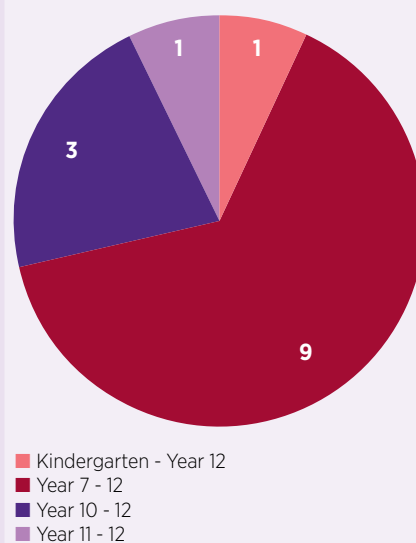


FIGURE 10: Geographic region

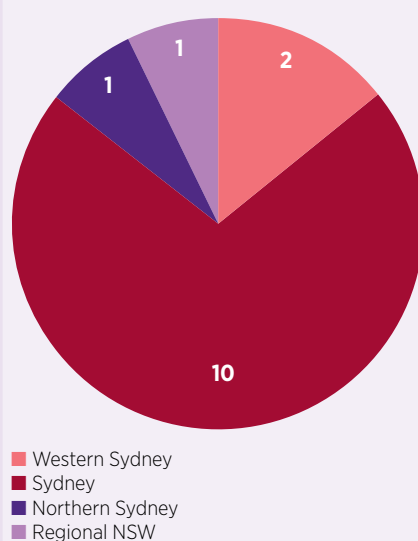
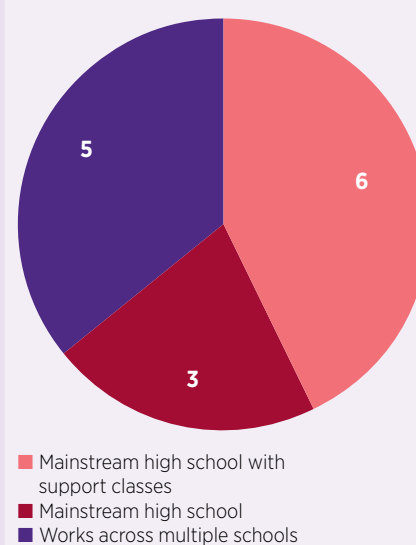


FIGURE 11: School type



**GROUP 4: DISABILITY EMPLOYMENT
AND SERVICE PROVIDERS**

FIGURE 12: Professional role of
disability service providers

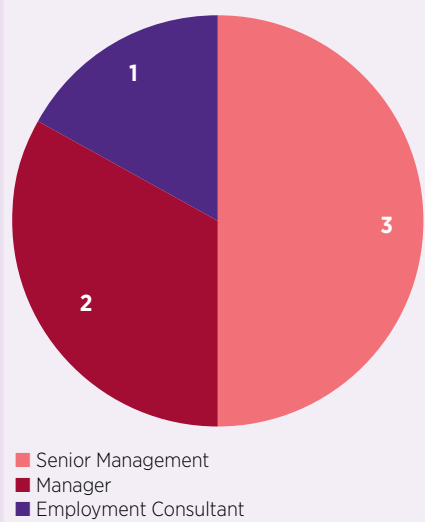
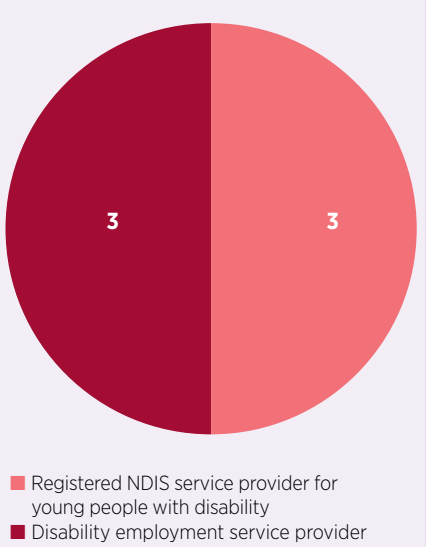


FIGURE 13: Employer





FINDINGS



EXPERIENCES OF THE TRANSITION PROCESS

EXPERIENCES OF AUTISTIC YOUNG PEOPLE

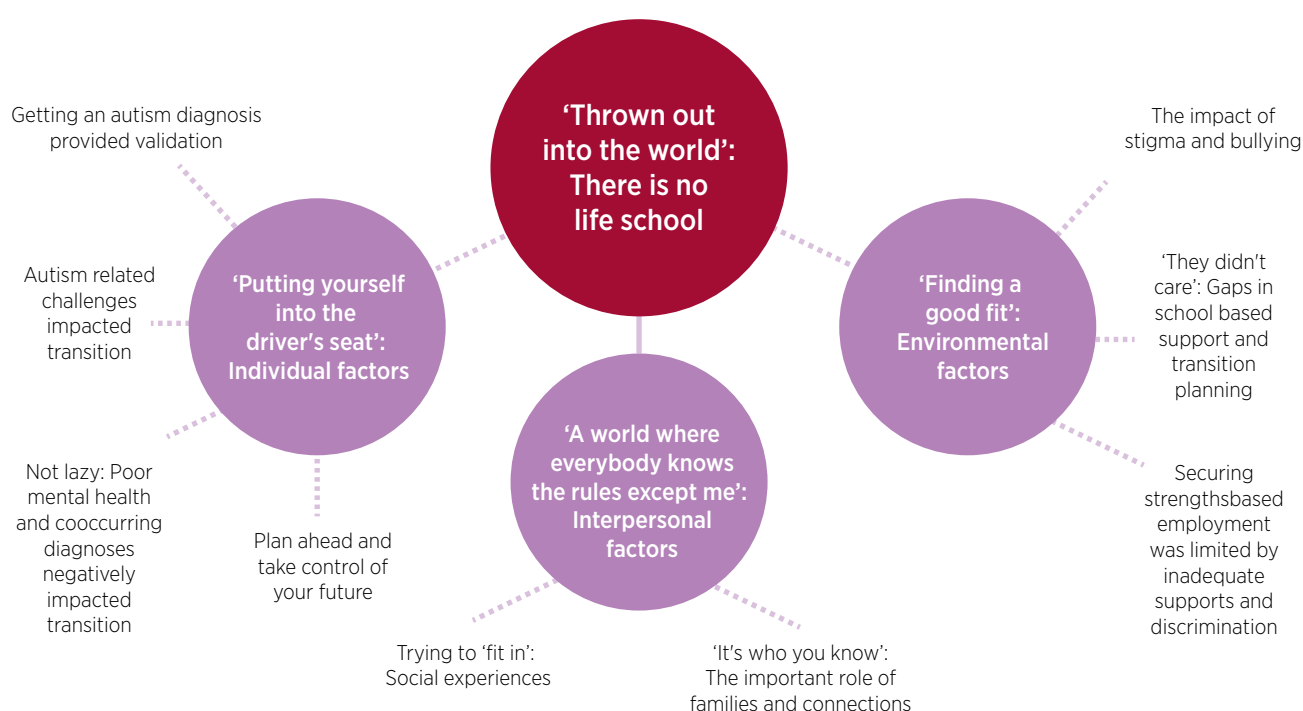


FIGURE 14: Autistic young people's experiences

THROWN OUT INTO THE WORLD: THERE IS NO LIFE SCHOOL

The perspectives of autistic young people around their transition from high school were represented by the overarching theme "Thrown out into the world: There is no life school". They highlighted a feeling of overwhelm and uncertainty when up to 13 years of schooling came to an end. While there were examples of positive experiences and supports across the

whole transition process, in general there were many gaps in transition support highlighted. Young people described a lack of sufficient specific and structured transition planning tailored to their goals, a feeling of being left without the skills for adult life, and limited connections and supports.

"You're just at school doing set subjects every single week and then you get thrown out into the world, it's like, what now... I was just thrust out into the middle of nowhere, nothing to strive for. I had no plans, I had nothing... I have been on this earth for 19 years, and a couple of months. And I have no idea how to function."

Young people reflected on the limitations of transition planning at school being focused purely on tertiary education or employment. They wished there was a “life school” to learn the vital skills needed for adulthood. Another autistic young person was “absolutely horrified” about the thought of leaving school and not being sure what was coming next.

“At least from Year 9 onwards, having at least one class a fortnight or something...teach you how to prepare for your adult life. Like learning how to do taxes. Organisation. Resumes. Job hunting. Job searching...a life skills sort of thing. That’s the worst thing that the schools are missing these days. There’s no life school.”

When asked to describe their thoughts about transitioning from school in just three words, young people’s perspectives highlighted a juxtaposition of feelings of uncertainty and worry mixed with excitement for the new chapter ahead, as seen in the word cloud below (Figure 16):

“I didn’t know there was any support out there...just kind of make your own way in life...it’s just going to be you in an ocean.”



FIGURE 15: Word cloud of autistic young people’s thoughts about transitioning

PUTTING YOURSELF IN THE DRIVER'S SEAT: INDIVIDUAL FACTORS

Getting an Autism Diagnosis Provided Validation

Some participants had gone through much, or even all, of high school without their autism diagnosis. They reflected on how “all the signs were there” and their frustrations of having to battle for a diagnosis to validate their lived experience. They highlighted how hard it was to feel in control of your life and to understand your challenges without understanding your neurodivergence. For some, this impacted heavily on mental health and self-esteem.

“I was relieved and happy that I finally have a label, and it also made so much sense...I thought I was just being a spoilt brat when I'd have tantrums and stuff, but I was actually having meltdowns... and it made a lot of sense, I thought I was just being picky and stuff, I didn't understand why my brain was doing this. And then I went through a period where I was really, really sad and upset because, I was like “why can't I just be 'normal', I don't understand.”

Before one participant's diagnosis post-school, she had been through school thinking “I was weird”, with others at times calling her “mentally retarded, like maybe she's got a learning disability”. When she reflected on how it felt having been undiagnosed for such a long time, the true impact on her sense of self became clear:

“[I was] Angry. Angry. Not going to lie...but that's why I'm in this field. I want to be a [health professional] because I want to help people that were like me, who need the help, who need to be picked up, who need to realise that having ASD is not a bad thing.”

Autism Related Challenges Impacted Transition

Young people also highlighted autism related challenges impacting their transition planning and experiences. This included struggles with motivation in areas outside of special interests, and executive functioning (planning and organising) required to get through everyday life.

A number of other individual factors were highlighted by young people as exacerbating their worries including immediate changes now and changes which may occur in future.

“Because of motivation, but also because of how I struggle with my own life. I can't plan things out accordingly. I can follow a schedule; I just can't make a schedule.”

“As it actually becomes a reality me finishing [school], I get nervous and I'm, like, oh, no, I don't have all my normal routine.”

“I wanted to move out for a while. It depends. Sometimes I really, really want to move out or I'll be like I don't want to move out, I want to stay in this house, I don't want to sell this house... so it gets very varied for me... because growing up so close with mum, it's a blessing and a curse sometimes... I'm so used to mum doing everything for me.”

Sensory challenges in new adult environments also created barriers for some during the transition period.

“The hard part is there are so many plans that are in things that I can't do, like, you know, I'm a uni student, what do uni students do? They drink, they go out to bars, and they have fun. I'm not at a capacity where I can do that, that's not something I can cope with, that's never going to be something I can cope with.”

Not Lazy: Poor Mental Health and Co-occurring Diagnoses Negatively Impacted Transition

Another individual factor influencing some young people's experiences of transition was the presence of co-occurring diagnoses, including mental illness. Young people highlighted the impact of autistic masking and social isolation on their mental health.

“It was also part of my depression because I just couldn't get out of bed and stuff, and then after I'd mask for the whole day and done stuff, I got so exhausted that I just wanted to lay in my bed and then I get told, “You're so lazy,” but, no.”

“like I wasn't in like the best of head spaces at the end of my high school years. So, I was in a very depressive sort of state because I didn't know what to do....and then once the reality set in, I was alone. I had nothing to do. Everyone was busy. And then I had lost all motivation to do anything”

“I mean, there’s a lot of sister conditions as well. It’s like Skittles, you never have just one. I mentioned dyspraxia earlier but for me I’ve got also generalised anxiety disorder, sensory processing disorder, I have friends who have ADHD and dyslexia, dyscalculia. With a lot of these sister conditions and with ASD you never have just one, a lot of people have a very unique combination of different disorders and disabilities... It’s like bingo.”

Advice from Autistic Young People: Planning Ahead and Taking Control of Your Future

Autistic young people offered advice for others in future and this advice included taking an ‘adult oriented mindset’ from early in high school, planning ahead, the importance of being self-reliant and taking control of your future.

“I’d probably say that when you first get to high school, you’ve got to realise that you’re not a child anymore and that one day, you will be an adult...whether you want to or not, you know, start trying to have a more...adult-like mentality.”

“you never know what is behind that door. Be determined, if you’re willing to overcome any doubts, then you can pretty much almost do anything.”

For some, part of taking control was learning to accept the adjustments and supports that were available in school and tertiary education. One of the autistic participants wanted other young people to know.

“Sometimes you may not feel like you need help but eventually, if you do get help, like support from teachers, family, and friends and all that, it actually will help you a lot.”

Part of taking control of the future also included coming to a sense of self-worth which was less influenced by others’ views.

“I think now I’m out of school, I’m more confident in – I don’t really care what people say.”

Others though, highlighted that for some autistic young people a positive sense of identify and capacity to self-advocate remains out of reach in adulthood.

“I’m lucky that I am able to advocate for myself, that I can open my mouth and know that I am safe, disclosing this and communicating - finding the words to communicate what I feel, what I mean, how I function... And a lot of people... don’t.”

A WORLD WHERE EVERYBODY KNOWS THE RULES EXCEPT ME: INTERPERSONAL FACTORS

Trying to “Fit In”: Social Experiences

In addition to the individual factors discussed above, participants’ perspectives reflected the impact of interpersonal factors on their experiences during the transition from school. This included struggling to “fit in”, to find social networks and supports where they felt they belonged, and also the influence of practical and financial support provided by family. One autistic young person summed up a common sense of not fitting in which was experienced by many participants.

“Throughout this whole process, it just felt like I was living in a world where every – we’re all in a game, like a giant game. And everybody knows the rules except me...you get a lot of these tight-knit sort of cliques. And I didn’t really fit in with any of them... there’s always this expectation that these people need to fit into a certain mould, and you don’t fit in that mould...you trap a whole bunch of like-minded kids – people trying to fit in – and then you have me. I just stick out like a sore thumb.”

Some young people expressed that they didn’t mind their lack of social connection, preferring to not interact with people unless it was necessary. Other autistic young people expressed a desire to have more friends, with some expressing sadness at their lack of social connection, expressing difficulties with engaging with ‘neurotypical people’.

“You know, neurodiverse whatever as I am, like I still have those sort of feelings and that sort of need to fit in.”

“To have a community, like to talk to, to interact with...to have a bigger group of friends...a bigger social group than I have now”

“Neurotypical people are weird... It still feels a bit weird for me because they don’t organise anything, it’s always me who has to organise things.”

Another autistic young person spoke of the challenge of learning social expectations as a way of fitting in. This was highlighted during the transition to new and unfamiliar adult environments where particular behaviours are expected such as tone of voice, eye contact and acceptable “things to say”. These behaviours may come easily to non-autistic people, but autistic people may longer to learn and “adapt”.

Some young people were buoyed by a sense of having found people in adulthood who accepted them.

“After years of not having friends and having this awesome group... they helped me, like I don’t know if I’d be literally here if they hadn’t become my friends...I have always struggled with friends, now I have an amazing group of girls and they’re very supportive and amazing.”

For others, fitting in meant finding a group of other neurodivergent young people to connect with.

“There were a bunch of other neurodiverse students who spoke up during the session last year, and the professor is neurodivergent himself, so he created a neurodivergent peer support network.”

IT’S WHO YOU KNOW: THE IMPORTANT ROLE OF FAMILIES AND CONNECTIONS

Another interpersonal factor which influenced participants’ transition experiences heavily was the level of financial and practical support that parents and families were able to provide. For young people without NDIS funding, families with the financial resources to pay for private therapies were at an advantage. Similarly, some had the capacity to pay for private schooling in the hope of securing more support for their child, or to consider transitional housing options like building a granny flat on their property to support a more independent adulthood. Practical measures to reduce stress and overwhelm were available to some young people. This included parents continuing to take responsibility for household tasks and driving their young person to and from work each day. Of course, these were not possibilities for all families and young people, highlighting the importance of being able to access the NDIS to ensure equitable opportunities during the transition to adulthood.

Another interpersonal factor which made a huge difference in the lives of some young people was the personal connections of their family and friends to facilitate access to employment. One young person found a job in a fast-food restaurant with the help of a friend, while another was offered work at his father’s workplace. One autistic young person described that he got a job “because my dad was friends with the boss”. It was clear that not all young people benefitted from such connections, again highlighting inequities during the transition period.

“it’s not what you know, it’s who you know”

FINDING A GOOD FIT: ENVIRONMENTAL FACTORS

Participants’ experience of the transition from school was heavily influenced by environmental factors outside their control. Trying to find “a good” fit as a neurodivergent person living in a world designed for neurotypical people was an ongoing battle for many.

“But for me, it’s a learnt behaviour... So when you take me out of an environment that I have gotten used to, okay, like my first high school or like my primary school for example, it takes me a long time to sort of adapt...it’s like learning the hard way and just a lot of trial and error.”

“The reality is there will be a lot of struggles because you are popping somebody with a differently built brain into a world that is catered for neurotypicals.”

THE IMPACT OF STIGMA AND BULLYING

Autistic young people expressed that not fitting in socially and being picked on and bullied was a common experience during high school.

“Like, I always knew I was different to other kids. And then so I’d tried even harder than other people so that I’d just be fit in, and just be normal, like fly under the radar, not even to be cool or anything, just so that I wouldn’t get picked on.”

THEY DIDN'T CARE: GAPS IN SCHOOL BASED SUPPORT AND TRANSITION PLANNING

Challenges remained through school, around accessing supports for “the social things” – the challenges of finding friends and meeting sensory needs in a busy school environment were highlighted.

Such experiences were extremely frustrating for autistic young people who felt they were “literally butting my head against a brick wall” trying to access the right supports and made them less inclined to ask to help in the future:

“I was having issues at school. They didn’t take those seriously because my meltdowns are implosive, I am not a chair chucking autistic, my meltdowns only really hurt me. So, they didn’t care.”

“I guess I’d learned through high school that even if you ask for help, you’re not really going to get it. So that just made me terrified to ask for help ever.”

When it came to support to plan the transition from school, some young people felt teachers and support people in their high school had been overly focused on one post-school pathway, transition to university, leaving gaps for those with different aspirations. Young people expressed that more support could have been provided to help young people to navigate the steps to a successful transition.

“He [careers advisor] was the kind of person who was trying to funnel everyone into Sydney University. There was no TAFE; there was no [getting a] job out of school.”

SECURING STRENGTHS-BASED EMPLOYMENT WAS LIMITED BY INADEQUATE SUPPORTS AND DISCRIMINATION

Beyond high school, similar challenges continued for a number of participants while trying to access support to find suitable employment. Disability employment services were viewed as not seeing autistic people as individuals with individual strengths and interests:

“These government agencies, they group people with disabilities all into one pile. You know, they think, ah, disability, can only do retail. Can only wash cars. Hospitality...it has to be one of those, you know? So they – like, they don’t see them as individuals, as separate people with different cognitive capacities and different life skills and different experiences, all of that. [We need] more understanding and more support. But not the... cookie cutter support that we have now...It’s understanding that there are different types of disabilities and different types of disabilities needs different types of support.”

Participants’ frustrations extended beyond employment services to employers themselves. They feared that disclosing their autism diagnosis would impact their employment chances and many knew this to be the case from personal experience. This was experienced by autistic young people with and without a university degree. A lack of education and awareness on the part of employers was highlighted as contributing to the difficulties.

“I have been searching for jobs for over two years... I’ve only ever been interviewed twice.”

“I applied for, like, hundreds, hundreds of places. All sorts of jobs, even retail, because I just needed a job. And no call backs, like at all.”

“When I graduated [from university], it was very tough, because I had a resume that wasn’t getting me anywhere. I had a few interviews. I did get a few interviews, but obviously they didn’t go well, because I didn’t get the job...it’s so very frustrating.”

“These employers need way more education on people with ASD... it’s not a bad thing. It’s not a liability. It’s not something that you need to coddle or treat them differently or something. It’s a different skillset that they have.”

When it came to the NDIS, nine out of the ten autistic young people did not access the NDIS, either because they believed they would not be successful, did not feel they required NDIS supports or they planned to apply in the future. One participant had successfully become an NDIS participant and said that one particular local service provider had made the difference, “fighting” the NDIS to get access:

“[The Service Provider] fought hard to get me in...she got me through everything that we needed”. This was a great relief after previously being denied access twice and after an entire year of Mum fighting and constantly submitting.”

EXPERIENCES OF PARENTS AND CARERS

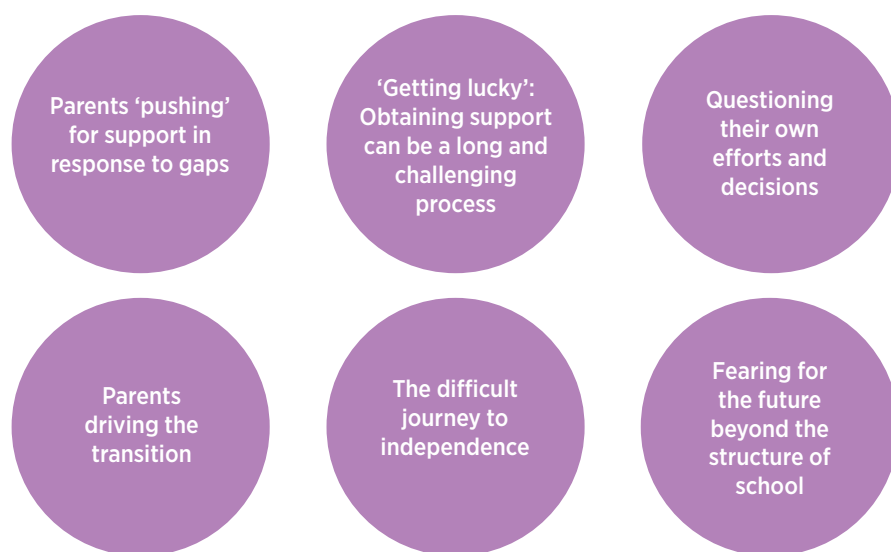


FIGURE 16: Experiences of Parents and Carers

PARENTS "PUSHING" FOR SUPPORT IN RESPONSE TO GAPS

Across the cohort of parent/carers, accounts of advocating for support for their young person were recurrent. Parent/carers described gaps in support, describing that they received no help or waited months to receive support.

"Months go by, and finally you get to meet somebody."

Gaps in support for autistic young people were exacerbated during the transition from high-school to post-secondary options which was highlighted as a particularly trying time.

"I think the most important part is the transition. You know, people tend to neglect that we transition them from childcare to primary. We transition them from primary to high school and then we, sort of, wipe our hands with them...so there's no transition to anything."

The challenges of accessing support resulted in parent/carers having to act as advocates for their young person, and "push" for support, with one carer describing themselves as "a bossy bitch".

"GETTING LUCKY": OBTAINING SUPPORT CAN BE A LONG AND CHALLENGING PROCESS

Acquiring support was said to be a lengthy and challenging process. One parent described the process of getting a disability parking pass from the Road Transport Authority as "the seven flaming rings of hell". When parent/carers were able to access support, they described "lucky" encounters with certain individuals.

"This person [at Northcott] has been a godsend...That's how we've got to where we are, pretty much."

One parent/carer highlighted that the system should not be built around people just getting lucky.

“The frustration that there just feels like there is no pathways to get support really, nothing that’s clear. But that said, when I have the capacity to, I chase things down, so that has resulted in us being quite lucky in some ways. But the system shouldn’t be built around people just getting lucky, working their butts off to try and make things happen, and then just getting lucky.”

When they were able to access support, parent/carers described feelings of relief and satisfaction, having worked hard to advocate for their young person, and seeing their growth.

“I literally felt like crying, I said, ‘I have been asking for three years, Year 6, 7 and 8, we need help, we need help; somebody help us.’”

“It’s been a very long journey. Yeah, a very long journey. But it’s very pleasing, the outcome, seeing how much [autistic young person] has grown.”

QUESTIONING THEIR OWN EFFORTS AND DECISIONS

In their role as support advocates for their young people, parent/carers questioned their efforts and decisions. The sibling carer questioned the choices they had made supporting their autistic young brother to seek acute mental health support:

“I felt like he was much worse than he was in high school. I actually was worried that did I make a bad choice of taking him into the hospital? Could it have been better if we didn’t take him to hospital?”

Some parent/carers expressed that they thought they could be doing more, while others said they had tried their “level best”, but despite this, were watching their young people fall “through the cracks”:

“You know like you see kids go through school and then they get to the end of Year 12, and they can’t read and the teachers are gobsmacked that they can’t read? I just felt [autistic young person] was that kid....I just tried my level best to not have him be that kid that fell through the cracks. And he fell through the cracks in front of my eyes which is heartbreaking because I did everything – I know I did everything I could.”

PARENTS DRIVING THE TRANSITION

In the absence of external supports, parent/carers worked hard to support their young person to transition to from school to post-school. They described supporting their young person to learn the practical skills they needed as such putting together a CV or doing regular chores to contribute to the household:

“Everyone in the house contributes to the house, whether it be a smaller contribution or a larger contribution.”

Personal connections were important for helping autistic young people find work and keep work, with many parent/carers describing their autistic young person found work through close friends or family. One of the parent/carers was able to help their young person to get casual employment at the parent’s own workplace and to advocate for the young person’s continued employment.

“We always employ several Christmas casuals and this is how [autistic young person] was able to get a start with [business]... All the tasks that we perform at work are well within his ability and capacity to do, which is very good.”

THE DIFFICULT JOURNEY TO INDEPENDENCE

In discussing young people's transitions from school to post-school, parent/carers described their young person's journey to independence, which required the young person beginning to take more responsibility for their own actions and decisions:

“At some point your child has to take responsibility for their own actions. You can't force them to study. You can give them the tools that help them learn...but you can't force them to do it.”

Despite their efforts to foster independence, parent/carers also spoke about their young person's ongoing need for support, which included supporting the young person with a broad range of tasks from managing their medication to social outings in the community. The journey to independence was often hindered by lack of available supports. This was highlighted by one parent/carer whose young person was experiencing difficulties with studying at TAFE:

“He's more dependent on me now than he was when he was in school. So, it's going the opposite way. And I need – I want and need to hand that over to other people for his own benefit as well. That he'd have a part-time job or some volunteering whilst he's finishing off his Cert III at TAFE. Just normal stuff...It just makes me sad because, you know, why should it be that hard for him just to have a normal life?”

FEARING FOR THE FUTURE BEYOND THE STRUCTURE OF SCHOOL

Some parent/carers were fearful of the transition out of school and losing the support and structure that school provided. One parent/carer described this kind of structure as a 'luxury' that stopped upon transition out of school:

“I've been enjoying the luxury of peace of mind, dropping [autistic young person] off from either primary school to high school. But now I'm faced with the reality I don't get that luxury anymore.”

With inadequate transition support in place, many parent/carers were fearful for their young person's future and the potential outcomes for their autistic young person:

“I've seen them. I've seen the outcome. If we don't do anything, if we don't intervene and improve our care, a lot of them are going to end up in group homes, become violent, become depressed, self-harm, all of that.”

“I even spoke to his year master about that, 'I'm so frightened about next year.' I was like, 'How is he going to get up for a job when he can't get up for school?'”

“I wouldn't want any of my kids to graduate from school to the lounge.”

One parent/carer said others, including professional and social supports had given up on her son, but she had to keep going with her efforts to support him.

“It's like everybody has kind of given up. And I can't give up because then what's going to happen for [autistic young person]? What's his future going to look like.”

EXPERIENCES OF EDUCATORS



FIGURE 17: Educators' perceptions

NON-ACADEMIC SKILL DEVELOPMENT AND WORK EXPERIENCE IN SCHOOL IS ESSENTIAL

Educators identified a number of important in-school supports that are necessary to assist young people to prepare for life after school. In particular, they viewed the inclusion of work experience and targeted skill acquisition to participate in the community as a core component of what school should offer to support transition.

“It’s about developing specific skills that are going to lead into the future.”

In-school work experience, accompanied by the development of practical on-the-job skills and daily living skills were seen as working in complementary ways to prepare the student for life after school. For autistic young people the invisible curriculum that guides one’s behaviour in the workplace and community, must become visible through deliberate skill acquisition support. This approach is presented as a way of achieving work experience out of school.

“when they get skills and a little bit of the trust and also some confidence, then getting them to do some work experience out of school.”

“Some of that independence and that living skills, whether it be folding clothes and personal presentation and organising, pretending that you’re going on a holiday, what are you going to pack, planning a meal.”

START THE TRANSITION EARLY TO PREVENT “FALLING THROUGH THE GAPS”

Educators expressed the importance of starting the transition process early and embedding transition within the school program. Some identified that conversations commence as early as Year 7 or Year 9 as it was critical to “get them early”.

Many educators reported that the transition process simply commenced too late and as such, the success of the process is undermined from inception. Starting early cultivates a preventative approach rather than a reactive one.

“We don’t wait for the wheels to fall off before we have to then put them back on. It’s much easier if we can prevent them falling off in the first place.”

In commencing the process early, the Individual Transition Plan (ITP) was cast as a key part of the transition planning. This school-based tool was presented as a way in which the student’s goals and subsequent supports could be identified.

“The strength of having an ITP, is that we’re going to be able to really focus on their skills that he needs for employment and within that, also focussing on what he wants to do.”

COLLABORATION BETWEEN STUDENTS, FAMILY, PROFESSIONALS AND SCHOOL IS ESSENTIAL

Collaboration between school staff, the autistic young person, their family and other support professionals was identified as an important part of transition planning and understanding the processes around transition.

“try and get as many influential people as we can into those... stakeholders, the therapists, the allied health, to really make sure that we’re doing everything we can to support that.”

For many educators, this collaboration was operationalised as structured meetings, typically, occurring at least twice a year where all key stakeholders who attend and participate.

“What’s really important is getting that collaborative meeting happening with the parents and the students, with and anyone else has an interest in that student as well.”

ACCESS TO POST SCHOOL STUDY IS INCONSISTENT AND RELIANT ON NON-ACADEMIC SKILLS

TAFE access and supports were mostly perceived positively by educators as an option for autistic young people following transition from school. However, there were reports that some TAFEs were selective in who they admitted and declined some students outright because of their perceived needs. University study may be an option for some students, but educators reported that disability supports varied depending on the university and that making initial contact with the university was important to support the transition. These reports mirror other accounts of inconsistencies in access and supports across the ecosystem.

“TAFE were really enthusiastic with the kids as well. And they’re kids with significant disability, so they’ll need a lot of adjustments, but if they need that, then they’ll get it.”

“they have good support once they’re there.”

“So make the contact with that service at the uni.... And they’re really good, because they generally have even a mentor, a buddy system, so can show them around the uni.”

“and so TAFE they ask you to go for an interview with their disability support team and they deemed she wasn’t suitable for TAFE.”

Educators recognised that success in a tertiary environment (TAFE and university) meant students had to meet academic requirements of various courses. A number of educators expressed that whilst students may be academically capable of university or TAFE study, they required support with non-academic skills such as social skills and travel training in order to be successful in this new environment.

“he got about 94.5 in the HSC, and he’s gone to do amazing things... But his social skills were very compromised.”

“we had one girl got into Maths at Sydney and she couldn’t get off at Central and she went all the way to Circular Quay, because she couldn’t actually initiate excuse me, I need to get off the train, you know?”

ACCESS TO SLES IS INCONSISTENT AND DES IS INEFFECTUAL

School Leaver Employment Supports (SLES) were perceived as being suitable for some autistic young people, with regular individualised supports offered that are beneficial for the young person's transition. However, concerns were expressed with the SLES eligibility resulting in inequitable access for autistic young people. If a young person does not have NDIS, they are not eligible for SLES, herein lies the gap. One educator expressed that SLES eligibility should be expanded beyond the NDIS criteria to include whether supports have been approved within the school environment.

“there should be a blanket SLES. At least – if you are in a support unit at the very least you’re eligible.”

For young people who are ineligible for supports under SLES, their only option is to access a Disability Employment Service (DES). However, supports provided through DES were reportedly insufficient to meet the needs of many autistic school leavers and reports about DES were overwhelmingly negative.

“DES is a complete waste of time.”

“There’s so much evidence it’s not working.”

“You know, we’ve still got incredibly high unemployment for people with disabilities. So the model’s not working, it’s broken, and you’re going to say that’s going to work for kids leaving school. Well, sorry, it doesn’t.”

One educator expressed that students received *“once a fortnight support and where they go into a centre and encouraged to go on a computer and look for a job. So not much direct support.”* Three more educators echoed this sentiment: *“There would be one or two because two hours of support a fortnight was just not going to be enough.”*; *“it’s averaging out about one hour a week, which is a disaster.”*; *“an hour is nothing.”*

Educators expressed that DES was inadequate in meeting the particular support needs of many autistic school leavers. This left a gap in service provision for autistic young people who do not meet the criteria for more intensive employment supports (SLES), but still require more support than DES provides.

“it presumes a level of capacity that a lot of young people with a disability don’t have”

WORK PLACEMENTS: SUPPORT AND ADVOCACY IS NEEDED TO ENSURE SUCCESS

Work placements are organised by SLES and DES providers as a means of securing paid work opportunities in the future. These work placements took a variety of forms, from ‘factory’ style supported work environments, moving onto more independent job placements. Educators described the merits of larger businesses which may have the resources and systems in place to support autistic young people appropriately.

“It’s pursuing those larger organisations that have the policies.... you will be looking at your McDonalds and your Coles and those sort of organisations to pursue.”

Alternatively, pursuing smaller businesses who may have a personal connection to disability may also be successful.

“...because they’ve got that experience and they know to break down those instructions, they’re doing it without even realising what they’re doing, you know, they’re really successful placements.”

Educators highlighted the important role of advocacy in ensuring employers with disabilities were willing, prepared and supported to give an autistic young person the chance to prove themselves.

“I think it’s talking to businesses about a person’s interests, and there’s some really fabulous stories within the community of big businesses that are creating employment opportunities that have actually increased their turnout or their [productivity].”

“Some businesses are not necessarily willing. Some it’s not accessible. A worksite needs, for someone with autism they might need a bit of extra support. And that person or that company can’t necessarily provide that.”

ACCESS TO THE NDIS IS CRITICAL, BUT REGRETTABLY, A MOUNTAIN TOO HARD TO CLIMB

“Some people see the NDIS as just a big mountain to climb, too hard.”

Although the primary focus of this research was to understand the experiences of autistic young people who did not access the NDIS, the NDIS arose as an important means of receiving supports, set up as a ‘one stop shop’ for funding disability services. This made getting support from the NDIS quite ‘high stakes’. Educators perceived that a lack of support provision under the NDIS placed extra pressure on families.

“So, when we say goodbye – the school leaver programs are all NDIS funded now. So as far as I’m aware it’s kind of like good luck out there without NDIS.”

“But if there’s no NDIS you’re depending on the parent really.”

There was a perceived gap between eligibility for support in school and eligibility for support under the NDIS, with young people often missing out on funded supports outside of school if they are not eligible for the NDIS. When a young person missed out on the NDIS, educators expressed sadness and concern for their future. Specific terminology used by the NDIS was perceived as a barrier, with the language being inaccessible and the use of categories and associated criteria inexplicable.

“Those kids that are not getting that NDIS support are not getting any of that input from outside providers miss out and the problem then is even more magnified when they leave school.”

When students miss out on the NDIS:

“I think it’s pretty sad for them... there’s a big gap for them.”

“For some of them, pretty grim.”

“They’re left behind, and they’re left out of the conversation.”

WHERE NDIS IS AVAILABLE, THERE ARE INCONSISTENCIES AND MINIMAL COLLABORATION WITH EDUCATION

Stories of successful collaboration between Education and NDIS were expressed where NDIS Coordinators within the Department of Education can connect with the Local Area Coordinators (LAC) and provide an extra level of support. There was, however, a sense that these successes were down to ‘luck’, in terms of who from the NDIS they have connected with. These inconsistencies within the NDIS system, where vast differences across personnel were evident, resulted in a process cultivating inequity and distress.

“I’ve been lucky. We’ve had good LACs but I’ve had families that haven’t had good LACs and I think that is the biggest problem.”

“We’ve already seen that you could hand in the same evidence to two different NDIA, and you’ll get two different outcomes.”

Educators were frustrated by the lack of consultation in determining a young person’s support needs and provisions under the NDIS. Although having worked with the young person and their family for a number of years, educators reported that silos between the NDIS and the education system meant that this knowledge and experience was not leveraged to benefit the young person in the establishment of their NDIS plan.

“Why can’t they just ask us? Like, why do they need all this when they could just come to us and just say you know, here’s [young person], you’ve known [young person] for the last four years. This is what I think she needs.”

THE IMPORTANCE OF FINDING YOUNG PEOPLE'S PASSIONS AND STRENGTHS

Educators spoke of the individuality of autistic young people and how this impacted their transition to life after school. Educators described the process of developing one's own identity and growing into an adult. They also recognised that having an autism diagnosis may play into this as young people learn how they are different and what strategies may be useful. Becoming an adult brings with it opportunities for independence, however, it was emphasised that a focus on strengths and interests is central to build a career.

“Letting student interest lead and letting these kids have a sense of ownership and autonomy and pride really.”

“...her goals are beauty therapy and hairdressing. So she – when she did her TAFE course last year, she absolutely loved it. She – it just lit up her whole life basically, and really have her some direction and passion.”

AUTISM RELATED CHALLENGES IMPACTED TRANSITION

Challenges were identified with autism characteristics including difficulties with the large change when leaving school which can be associated with anxiety and uncertainty, and difficulties with social interactions which are inherent in the transition experience.

“What was always such a constant for them, and it has been since kindergarten, the idea of school, Monday to Friday. I get up. I go. School holidays. Like it's very regimented. It's been the same since kindergarten... Then there's a significant difference as to what happens after school. So, yeah, there's certainly some anxiety involved there.”

“It's overwhelming leaving school, it's exponentially worse when you're leaving school with a disability.”

FAMILIES ARE TOUTED AS THE DRIVERS, BUT ENGAGEMENT AND ADVOCACY CAPACITY VARIES

While educators themselves saw they had a role in helping families navigate transition, they reported that families were the main drivers, with educators limited in their capacity to make decisions.

“but ultimately, it's the parents that drive it.”

Although the narrative of 'parents as drivers' was touted by educators, the language used by educators positioned the educator's role as 'engaging' the families and thus it remains unclear if the practice of who is in the driver's seat matches the rhetoric.

Partnering with and engaging with families was perceived by educators as a key part of transition planning where they sought to engage early and share resources with each other. Educators expressed that they seek to talk with families to understand their goals and what supports are required. Consistent with the idea of 'parents as drivers' some educators explained their efforts to encourage families to lead the transition process.

“Talk to the families about their goals, what do they want for their children, what kind of supports we can put in place if they're not getting something, if they don't have NDIS funding.”

“I always say to my parents, you need to have this career path when you're leaving year 12. You know, you need to know where you're going.”

If the current system relies on families to ‘drive’ the process, educators reported that within the current transition system, some families were better equipped than others to advocate for the needs of the young person. This results in further compounded inequities where families may not be able to work effectively in the transition process, to the detriment of the young person. Again, inconsistencies in outcomes arise for individuals that is dependent on the capacity of people around them.

“I think it does come down to what connections you may have within your family or within your social network and it goes from there, and that’s where our at-risk members of society, and then add the disability are so, so disadvantaged because they really just have that.”

“They’re relying on their family to advocate. I think one thing you can take from this perspective out here is I do see a lot of students with disabilities in out-of-home care who have no family advocacy whatsoever.”

Educators perceived that a range of family characteristics may impact their engagement with transition planning including family ruptures, poverty, parental disability, trauma backgrounds, mental health issues, and cultural and language diversity.

“They’re just so dysfunctional, some of them.”

“Their home lives are very, very complex. Lots of out-of-home care, lots of kids either single family or living with grandparents, many, many below the poverty line in housing and other such.”

“So most of those families, they’ve been really difficult families to get up to schools. They don’t have a history of engaging with the school... So some of those families that are even hard work.”

Additionally, some educators perceived that parents may not wish to engage in school-based processes related to their child’s disability due to a history of their own trauma with schools or their emotional relationship with their child’s diagnosis. For example, parents may not be ready to have such conversations as they grapple with the grieving process around having a child diagnosed with Autism or the cultural beliefs and practices around disability.

“So for a lot of students there’s a cultural reason why they won’t put these kids into support units or access funding, or integration ...or a diagnosis, because culturally you don’t.”

“...reaching the HSC, ... a lot of those students really flounder, particularly where the parents were not able to come to terms with the fact their child has a disability.”

“for some parents, it’s a grieving process as well. You’ve brought this baby in the world and they’ve got a disability.”

EXPERIENCES OF DISABILITY SERVICE PROVIDERS



FIGURE 18. Disability Service Provider perspectives

STARTING THE TRANSITION EARLY TO PREVENT "FALLING THROUGH THE GAPS"

When describing the transition from school to post-school for autistic young people, disability service providers (DSPs) highlighted the importance of starting the transition process early. This enables DSPs to build a relationship with the autistic young person, getting to know their strengths and interests. This was perceived to be beneficial for autistic young people, aligning with the way they learn.

"If I had a magic wand, I would start that process earlier in school, in education, start it there. Don't wait till they come out of school, and all of a sudden, they're left in the big wide world..."

DSPs expressed concerns that not starting early would result in young people "...falling through the gaps". One Service provider expressed the importance of supporting young people before they turned 18.

THE GOOD AND THE "NOT SO GOOD": INCONSISTENCIES BETWEEN SCHOOLS

DSPs said there were "good" schools that had "greater understanding" of how to support autistic young people. However, other schools were "closed off" and merely "ticking the boxes".

"There may be a handful of schools out there that actually put in correct time and attention and training for these kids...there are maybe a handful of schools that are great like that, but most of them, I'd say 75% of them are – they just want to get rid of the kids. They're not helpful at all."

The same inconsistencies were described when talking about individual teachers, with some described as being 'excellent', while others were not.

"There's good teachers, and there's not so good teachers."

"NO SUCH THING AS ONE SIZE FITS ALL": INDIVIDUALISING SERVICES

When supporting autistic young people, DSPs emphasised the importance of flexibility, individualising services and supporting young people to maintain their uniqueness and be themselves. There were different opportunities required to meet the needs of different young people. Treating young people as individuals was part of how DES providers distinguished themselves from other recruitment providers.

"We just treat everyone as you would like to be treated and everyone is an individual, so, even if you didn't know what their condition was, you would get to know them and help them to find employment."

THE IMPORTANCE OF FINDING YOUNG PEOPLE'S PASSIONS AND STRENGTHS

Identifying the interests and passions of autistic young people is important when providing support and is related to the previous theme of individualising supports. DSPs described the importance of finding the young person's preferences and passions and working towards the young person's goal.

"It's very much, someone comes to me and says, 'I'm really good at fixing push bikes', but has never worked and would need a lot of support, we don't just have an employer that we can go to but we individualise our service to suit what that person's skills are, what their interests are."

"If you are individualising the service and they get a job that they love and their really interested in and it suits their skill set and their capabilities, they are going to be in it for a long time and that's what we are here to do: long-term employment."

The interests and passions of autistic young people are commonly ignored in employment support services, with young people being directed towards shelf stacking or other low-level labour. DSPs described that this was often unpalatable for autistic young people and incorporating a young person's passions may result in better employment outcomes. These outcomes should be monitored by DSPs as a critical part of the process.

“Identifying where the – that – that kid fits in, you know, where they – what they’d like to do, um, then build those talents, you know, give them opportunities in those areas that they enjoy and they will probably get better outcomes.”

FINDING THE RIGHT WORKPLACE FIT IS CHALLENGING

Employment solutions for autistic young people need to meet the needs of both the autistic young person and their employer. Finding an employer who understood the young person's needs was important in this process.

“We need to find an employer that will understand that individual person and open communication, open about what’s going on and then we are a mediator in between, to try and help.”

Service providers often saw themselves as the ‘mediator’, ensuring a good fit between the autistic young person and the job role. DSPs also perceived that they had a role in ensuring the autistic young person had the required skills for the job.

“There’s been a lot of barriers, like, a lot of issues since he’s been at work but then we go to the workplace and support them to help with any of those issues.”

“FILLING A GAP”: EMPLOYMENT SERVICES FACILITATING ACCESS TO THE NDIS

One disability service provider described their willingness to support a young person's access, however, this was partly the role of the NDIS, and they felt as though they were taking on tasks which were the NDIS' job.

“I’m happy to help you to find the job but there’s a lot of other programs that are available as well...that’s how with the community connector, I always invite them to come and meet with them, but that’s their job [NDIS], I’m just doing their job for them.”

DSPs described their role in filling a “gap” in NDIS services, supporting young people to step through the process of applying for the NDIS which included filling in forms and other tasks. Supporting a young person to access NDIS, while not traditionally the role of a DSP was viewed as a critical task in supporting the young person to move forward and be successful in their life.

“...life skills, like, he can’t read his payslips...Learning how to cook meals at home and pay bills. He doesn’t know how to read and write, so he can do his job...I think, with an NDIS plan to help him with all of those things and if he was able to move out of his parent’s home and live on his own, he would be much happier at work. So, it all does affect employment, so that’s how I got around that helping him.”

REPORTED ENABLERS AND BARRIERS TO TRANSITION

FOR AUTISTIC YOUNG PEOPLE

The detailed experiences of autistic young people, parents/carers, educators, and disability service providers presented above highlight a range of enablers and barriers to a successful transition from school for autistic young people. The collective experience of all stakeholders provides guidance for how best to support and improve the transition process.

ENABLERS TO SUCCESSFUL TRANSITION

BARRIERS TO SUCCESSFUL TRANSITION

Starting the transition process early.	When the process of transition starts too late.
Getting access to work experience and job-related training while still in school.	Gaps in service eligibility between school and post school. Eligibility for disability supports in school is different to eligibility for support under the NDIS, leaving a gap in service provision.
Gaining enough support for both academic and non-academic skill development (daily living skills, community mobility).	Inadequate school leaver employment supports for autistic young people.
Collaboration between all key stakeholders including the young person, their family, teachers and relevant health professionals and the NDIS.	Incongruence between how schools report about disability and how the NDIS require their reports to be written.
A well-resourced 'switched on' family to drive the transition process.	The Administrative burden of the NDIS- getting the right paperwork and understanding the terminology.
Information, knowledge, or experience in the community sector and professionals who support autistic young people.	Costs associated with accessing assessments required by the NDIS to facilitate access.
'Out of the box thinking' by professionals who support autistic young people.	Inconsistency and rigid funding structures in terms of how disability support is allocated.
Recognising the individual strengths, skills and interests of an autistic young person when supporting them to get a job.	Lack of time and/or willingness for coordination and collaboration during the transition planning process.
Having the right professionals in place to support autistic young people and their families to navigate the transition from school.	'Buck passing' and the 'blame game' resulting in a lack of clarity about whose role it is to provide the support.
Having the funding in place to pay the right professionals (through NDIS or other sources).	Lack of Autism-specific knowledge and how to effectively support autistic people in the workplace.
Patience and perseverance on the part of autistic young people and the people who support them.	Lack of appropriately qualified professionals on the ground who can support families in the community.
	Not enough support professionals in schools to support young people including STTs and allied health professionals.
	Stigma and discrimination about autistic people and their capabilities.
	Deficit based systems in place in the disability sector.

THE IMPACT OF COVID-19 ON THE TRANSITION PROCESS

Given this research was conducted during the COVID-19 pandemic and subsequent lockdowns, it was opportune to assess how this new way of studying, working and living might either enhance or hinder the transition process to inform future practice.

THE GOOD AND THE BAD OF ONLINE LEARNING

Online teaching and learning became a regular occurrence during the COVID-19 pandemic and associated lockdowns. Participants held varying perspectives around the challenges and opportunities of online learning, through school, TAFE or university.

The most salient concern about online learning and learning from home was the observed reduction in motivation and engagement of young people. Young people, parents and educators all witnessed this change in behaviour, with a few young people acknowledging that this lack of motivation resulted in reduced grades.

“I work best on campus personally because it was, like, oh great, my anxiety’s gone, oh shit, my motivation’s gone... I personally don’t work like that, I need to be in a classroom, be held accountable for doing these kinds of things, that was the period when I found a lot of my deadlines were slipping because I didn’t have the motivation to keep on top of everything.” (YOUNG PERSON)

“There was less attention paid to school because videos are very boring, and he worked out ways to trick the system. So he’d turn off his camera, and he put his earphones in, and he said, you could go the toilet, he could get himself something to eat. He’d roam around the house, and I’d be like, “What are you doing?” “I’m in class.” “Yeah, class, really? Shouldn’t you be in your bedroom on the computer?” (PARENT)

From the perspective of educators, online teaching was largely perceived to negatively impact the teaching and other supports that educators normally provide to students. One educator expressed that hands on learning support was required for autistic students, which was not possible through online learning.

“I guess, with kids with special needs, they need that hands on, they need a bit of scaffolding, they need a lot of that. They have an inability to stay focused for too long.” (EDUCATOR)

Another educator reported that online learning reduced the capacity of teachers to teach and support their students.

“So they need that where the teacher can read that they’re losing the student and have the flexibility to move onto another task. On that online learning you don’t get that. And I think also, to keep them further engaged in their learning they need that variety, and the online learning was just one tool that we could provide.” (EDUCATOR)

This was not the case for all young people, with one parent explaining that their child focused very well on this new platform and achieved pleasing outcomes. Similarly, one educator reported that zoom offered another of connection by bringing people into their house.

The shift to an online environment allowed school-based students to access online learning opportunities run by outside disability service providers without having to travel. There were also some benefits identified by young people around the technological advances in job recruitment that grew through COVID-19. The movement of applications and interviews online served some young people well because it reduced the social pressures.

“Applying for jobs in COVID has been much easier than actually applying in person. Because everything is moving online, we’re having to do video interviews, talking to a screen. We’re not talking to an actual person.” (YOUNG PERSON)

“So the student – like the teachers are often looking for like short, sharp, kind of one hour sessions that run a couple of times a week or once a week, that they can get the [students] involved in at school, so they don’t have to travel.” (EDUCATOR)

REDUCED SUPPORT

It was evident that the majority of participants believed that COVID-19 lockdowns restricted access to support that would normally have been available for autistic young people. These restrictions extended across many of the services and supports for transition.

High school students planning for post-school services were limited in their opportunities to explore various options, with access to work experience and job fairs being the most affected.

“As far as giving you opportunities to have a look around in other potential post-school options, as far as service providers go, that’s one thing that’s just had to be cancelled.” (YOUNG PERSON)

“It [job fairs] stuffed up this year because of COVID, it was all online and it was disastrous.” (EDUCATOR)

“We haven’t been able to have work experience, a lot of those, particular with autism, you need that transition and that predictability, and the structures, it just hasn’t been here this year.” (EDUCATOR)

“We haven’t done anything on work experience wise. It’s pretty much COVID just sort of knocked it out of the water last year and it hasn’t recovered. So, our careers advisor, I’ve been talking with him and he’s saying businesses are just not taking on students. They’re still very worried about what might go wrong so they’re just saying no.” (YOUNG PERSON)

COVID-19 lockdowns also impeded the support which could be offered by Support Teacher Transitions and NDIS Local Area Coordinators for high school students embarking on the transition to post school. This issue contributed to an increased workload for educators.

“Because of COVID, none of my families are coping with remotely communicating to LACs looking for help, asking for help ... I’m the one that’s ended up doing an awful lot of stuff that – probably a year ago I was starting to refer to NDIS and the LACs, and this year it’s back to if I don’t do it it’s just not happening.”(EDUCATOR)

Those who were engaged in programs such as School Leaver Employment Supports (SLES) or TAFE reflected on how the services had changed due to COVID-19 lockdowns resulting in less support for the autistic young person.

“It was very hard, he had to do, mainly do like some of the interviews via Zoom, disability option and yeah, they pointed him in the right direction but yeah, he had to, himself, had to apply for the job.” (PARENT)

“[TAFE] do not allow our – any of our staff into classrooms. So they – so I’m not allowed to go and observe a session, for example. The support services aren’t allowed.” (EDUCATOR)

SOCIAL ISOLATION AND IMPACTS ON MENTAL HEALTH

“Mental health stuff has gone through the roof.” (EDUCATOR)

Participants reflected on the negative impacts of COVID-19 on the mental health of autistic young people, largely exacerbated by enhanced social isolation and heightened anxiety about the threat of the illness and the uncertainty of the future.

“It affects me a lot because I think about how much time I spent alone... and yeah, I have had some times where I could break down... not a good feeling – being trapped inside for this amount of time. Because it can take a huge toll on your mental health. I know it has happened to me, especially at the start of the pandemic. And it’s impacting a lot of my friends as well.” (YOUNG PERSON)

“He’s still maintaining that isolated ethos, that, you know, this is the new world, or ‘No, I’ve got a cough or I’m sneezing today so I can’t go anywhere. I don’t want to infect people’; ‘I don’t want them infecting me’; so, we’re still on hyper-alert.” (PARENT)

“Like there’s very high anxiety levels, I think, in the senior students due to COVID, and I think it’s all to do with the uncertainty of COVID and what happens and what’s going to happen and what are my options and – yeah, across the board, very high levels of anxiety”. (EDUCATOR)

LIMITED EMPLOYMENT OPTIONS

Limited employment options were a negative consequence of COVID-19 for young people with businesses reducing the number of people they employ. Autistic young people found the impact of COVID-19 on their job prospects very “stressful” (young person).

“Well, no-one’s hiring. This is the big problem. No-one was hiring. People were going into lockdown. It was a scary place. It was a scary time. Probably the worst thing that’s ever happened to anyone.” (YOUNG PERSON)

“[YP’s workplace] closed down during COVID and then they opened up last October a year ago, and then he worked from just the October till December. And then the COVID hit again. So yeah, he was the last on, so he was the first off.” (PARENT)

DISRUPTIONS TO ROUTINES AND IMPACTS ON MOTIVATION

The COVID-19 pandemic resulted in widespread disruptions to established routines for autistic young people. This was challenging and it was difficult to maintain motivation through this period where the routine was interrupted.

“I would say the hardest part is maintaining that drive, that determination. Because, especially during COVID, I think it was hard to keep going.” (YOUNG PERSON)

“[For] people with autism, very routine, so there was a lot that didn’t cope. Very overwhelmed, lots of panicking. It was pretty crazy.” (DISABILITY SERVICE PROVIDER)

After the lockdowns had ceased, challenges were encountered with motivating young people to “get back out there”.

“Yes, I organised a case conference a month or so ago with all of his key people saying, right, how do we get everything going again and transition [autistic young person] back into his typical routine? So, we brainstormed some ideas, like reduced hours and reduced days. And unfortunately, it still hasn’t worked. So, we’re just in this limbo land at the moment, and it’s just day by day. So, all the doors are still open, and every morning I’ll wake [autistic young person] up and say, okay, come on, today you’ve got Northcott, or whatever it might be, let’s get up and give it a go. And it’s just a “no, no, no, not doing it”. I can’t force him, he’s 19. We talk about the pros and cons, the consequences and possible outcomes, and his goals et cetera, but nothing will motivate him enough to get back out there. And that worries me a lot.” (PARENT)

GREATER COMFORT AND LESS STRESS

Despite the challenges created by COVID-19 some young people reflected on the positives it had brought, including an opportunity to slow down and not do as much.

“As much as the world is still in havoc, but it’s been kind of peaceful not having to try and worry about things. So I’m not actually having to worry about doing much.”(YOUNG PERSON)

Some participants perceived that being at home was preferred by the young people as they felt safe and comfortable at home. Being at home also eliminated some of the challenges associated with being at school, for example the playground, or the expectation that they should be working.

“Well, on the positive, he’s been happier because he’s at home where he feels safe and comfortable and less stressed. So, he’s enjoyed that.” (PARENT)

“My school shut down and I wasn’t able to go to school which I was happy about. I was so happy, I was living, I was, like “oh, no school, yay.” (YOUNG PERSON)

“But a lot of them have loved being at home. No sort of social interaction on the playground.”

(EDUCATOR)

Whilst at first glance the reduction of stress may be perceived as a positive outcome, one parent lamented that reinforcement of avoiding stressful social situations makes it difficult for autistic young people to resume their interactions in the world.

“He’s got all the funding there and the structure there to support his goals to work with animals. But it’s just not working because he’s so depressed and anxious. So the mental health, and then obviously the pandemic, everything stopped, and he got into this rut where he’s very comfortable; he likes the rut. It’s nice and safe. There’re no expectations, no unwanted social connection or stress.” (PARENT)







NINE KEY FINDINGS ABOUT POST SCHOOL TRANSITION

1	The transition to post schooling for autistic young people is fraught	All stakeholder groups reported that significant challenges were experienced by autistic young people when transitioning from school.
2	Every autistic young person's experience is different	There isn't one universal experience for autistic young people. Similarly, their strengths, challenges, interests, and goals vary. The transition process must recognise individuality.
3	A deficit view prevails where the autistic young person is viewed as the problem to be fixed	Participants largely focused on how young people should be supported to overcome their challenges so they would be fit for post schooling. Less was said about how the post schooling environments should be designed for all.
4	Young people want a chance to prove themselves	Autistic young people want employers to give them a chance to prove themselves.
5	There is limited support for autistic young people and their families	Autistic young people can lack support, particularly when it comes to transitioning from school to post-school.
6	The complicated and limited access to appropriate funding locks out autistic young people in need.	The process of accessing appropriate funding (including NDIS funding and other types) is difficult and the eligibility criteria is restricted, with some people missing out and falling through the gaps.
7	There is a 'siloed' approach to supporting the transition which results in gaps	Participants often blamed failures on the other stakeholders in the ecosystem. This resulted in gaps in service provision. It remained unclear who was 'driving' the process.
8	Inequity arises with inconsistency of supports: a good outcome depended on "luck" rather than a good system	Widespread inconsistency of supports was reported from the stakeholder groups. A good outcome came from being 'lucky' with parental capacity, NDIS LACs, teachers, employers, TAFE or university. Such systematic inconsistencies breed inequities where those most vulnerable are further disadvantaged.
9	COVID-19 exacerbated difficulties	The COVID-19 pandemic and lockdowns resulted in diminished support and poor motivation and mental health for autistic young people.



SEVEN KEY RECOMMENDATIONS TO OPTIMISE POST SCHOOL TRANSITION

1	Transition planning needs to start early	Transition planning needs to start early as an ongoing process throughout high school. Collaboration and clear role delineation is required with a potential for adopting a key worker model.
2	Improve awareness and capacity of workplaces. TAFE and Universities	Much of the findings reinforced a deficit model. There is a need to strengthen universal design in schools, tertiary education environments and workplaces. Stigma and discrimination about neurodivergence should be challenged.
3	Adopt an individualised approach, driven by an autistic young person's passions	Strengths and interests of autistic young people should be recognised as something which can be developed and lead to a career. Young people need support to take a leading role in planning for their future.
4	Expand access to intensive school leaver employment supports like School Leaver Employment Supports (SLES)	Re-assess the Disability Employment Service (DES) model and expand access to more intensive employment supports for autistic young people, especially when they are unable to access the NDIS or other funding options.
5	Support the mental health of young people and parents	The mental health of young people and parents should be prioritised. Not only is positive mental health an important outcome in its own right, but it is also foundational to navigating a successful transition.
6	More resources and access to work experience is needed in schools to support young people to prepare for transition	More resources are needed to support transition – including Support Teachers Transition (STT), allied health professionals in schools and tailored services for those not eligible for NDIS. Work experience in school is essential for success.
7	Raise their voices	Bring the voice of lived experience into individual planning and systemic processes to optimise their application and success.

RECOMMENDATION 1: TRANSITION PLANNING NEEDS TO START EARLY

The need to start planning for transition early was consistently identified by all the stakeholder groups who were interviewed. Working towards transition should be embedded in schooling for autistic young people from year seven. Collaboration between key professionals, autistic young people and families is key and roles should be clearly identified and agreed upon throughout the planning process.

One successful model which could be explored is the 'key worker' model, where a young person's care is coordinated by one key person who has the responsibility to partner with the person and their family to coordinate services across systems and across time. Key worker roles may be adopted by a wide range of professionals including occupational therapists, psychologists and teachers.

RECOMMENDATION 2: IMPROVE AWARENESS AND CAPACITY OF WORKPLACES, TAFE AND UNIVERSITIES

Findings from this report reinforced a 'deficit model' of disability where the 'problem to be fixed' sits largely within the individual as a function of their disability. There was a deafening silence around the issues present in post-school environments which may hinder success. A move towards more 'universal design' which aims to make environments, activities and learning opportunities universally accessible is warranted. This model is promoted in schooling for younger children and should be adapted and implemented in tertiary education settings such as TAFE and university as well as supported and open employment settings.

RECOMMENDATION 3: ADOPT AN INDIVIDUALISED APPROACH THAT IS DRIVEN BY A YOUNG PERSON'S PASSIONS AND STRENGTHS

The importance of recognising an autistic young person's passions was commonly reported across the stakeholder groups. When a young person's passions were identified, there were a number of perceived benefits including a greater level of skill and motivation from the young person, which could be used successfully in a job placement to the benefit of both the young person and their employer.

To facilitate this, time should be taken to work strategically with a young person around identifying their passions and how this could be shaped into a career. This may be achieved through a modified person-centred planning approach commonly adopted in adult disability services. Critical to this approach is the agency and meaningful participation of the autistic person in planning for their own transition. Future work could involve the development of a person-centred planning tool which could be used by professionals and autistic young people to facilitate this process.

RECOMMENDATION 4: EXPAND ACCESS TO INTENSIVE SCHOOL LEAVER EMPLOYMENT SUPPORTS LIKE SLES

Participants mostly reported that the current model of DES is not working effectively to support autistic young people to transition from school into employment. SLES offered more intensive employment support, but the eligibility criteria for access is too narrow, with only NDIS participants eligible for SLES. Autistic young people reported that employment supports were hampered by a lack of resources and availability as well as stigma and discrimination. Parent/carers and Educators echoed this sentiment and highlighted the need for better access to a system of intensive employment supports and job placements which recognise the individual strengths and interests of young people.

SLES programs should expand their eligibility to capture more young people with disabilities, with autistic people gaining eligibility for SLES if they had identified support needs in school, irrespective of their NDIS eligibility.

RECOMMENDATION 5: SUPPORT THE MENTAL HEALTH OF YOUNG PEOPLE AND THEIR PARENTS AND CARERS

Mental health concerns of young people and their parents were identified as a barrier to successful transition. This was exacerbated during the COVID-19 pandemic and associated lockdowns.

Mental health should be prioritised in all transition plans as it is a key requirement to foster further aspirations like employment, further education, and participation in the community. Mental health promotion has been adopted in schools and the community more broadly, but this is not necessarily tailored to the specific needs of autistic people and their families. A 'siloed' approach to mental health and disability means that people who have both a disability and a mental health concern may not get the targeted support they need.

RECOMMENDATION 6: MORE RESOURCES AND ACCESS TO WORK EXPERIENCE IS NEEDED IN SCHOOLS TO SUPPORT AUTISTIC YOUNG PEOPLE TO PREPARE FOR TRANSITION

Educators reported that schools are currently under resourced and struggling to keep up with providing support to the volume of school leavers with disabilities who require supports, beyond the classroom. Autistic young people and families reported that they felt unsupported by the schooling system, with positive support provided by the good will of individual educators rather than systemic supports.

Resourcing should be expanded to support more Support Teacher Transition (STT) positions as well as allied health professionals such as occupational therapists, psychologists and speech pathologists to work alongside teachers in supporting skill development required for life after school.

Supported work experience throughout high school where the young person progressively builds confidence and skills is essential so that participation is embedded into their experience and expectations as a young adult.

RECOMMENDATION 7: RAISE THEIR VOICES

Too often, important decisions about autistic peoples' lives, or the systems and processes designed to support them, are made by well-meaning non-autistic people with inadequate meaningful consultation with autistic people. Incorporating the lived experienced of autistic people into systems and organisations that make decisions about autistic peoples' lives is critical, as well as the leadership of autistic young people in their own transition planning.

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