



Reaching Potential

Experiences of young people with significant intellectual disability

SVA Consulting

Limb Family Foundation 

Anthony Romagnano,
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Contents

1.	Executive Summary.....	2
2.	Introduction	5
3.	Methodology.....	8
4.	Stories of people with significant intellectual disability	9
	Case Study 1: Connor and David	10
	Case Study 2: Nathan and Jodie.....	12
	Case Study 3: Katherine and Lisa.....	14
5.	Discussion	16
	Theme 1: Rich and diverse aspirations.....	17
	Theme 2: A meaningful life of education, work and community participation	19
	Theme 3: A secure future	27
	Theme 4: Robust disability services	32
	Theme 5: Healthy living.....	40
	Theme 6: Community attitudes	44
6.	Covid-19 Reflections.....	46
7.	Conclusion.....	48

Executive Summary

Young people should all have the chance to pursue lives of their choosing – lives that are rich with opportunities to learn, work, connect with others and engage in the community.

This should not be different for young people with intellectual disability. Yet these young people face barriers to accessing the support, services and experiences they deserve, driving inequities in health, education, social and economic participation outcomes.

This report explores the experiences of young people with intellectual disability, focusing on those with more significant support needs. It presents various life journeys of young people from across Australia, identifies system gaps that are driving challenging experiences and opens a conversation about what is required to improve outcomes for them.

Across our study, we identified six themes as key influences on the experiences of young people with intellectual disability. These themes represent a mix of systems, behaviours and drivers that collectively shape the make-up and quality of life of a young person with intellectual disability. The report also includes perspectives on priority actions to drive better outcomes and deliver meaningful improvements to the lives of these young people. These actions build on the collective knowledge, learnings and existing efforts from across the sector.

We hope that the included stories, insights and observations provide a foundation for the design of flexible service systems that recognise the uniqueness and diversity of this cohort and drive better outcomes for all.

Insights into action



Theme 1: Rich and diverse aspirations

Supporting young people to realise their aspirations is an enduring aim for carers and families and needs to represent a central focus of the service system. However, we found young people with intellectual disability are not always appropriately engaged in goal setting, which leads to missing links between potential supports and their aspirations. Barriers to communication and self-advocacy can lead to tensions and exclude them from conversations about their aspirations and goals, particularly with decisions that impact on their ability to achieve them. While there is recognition that goal-orientated services are critical in establishing a quality of life, there is little agreement or clarity on what this looks like for supporters and young people alike.

A focus and set of efforts is required to ensure young people are given real opportunities to meaningfully participate in goal setting. To do this, young people need to be provided with the information and supports required to appropriately engage with and contribute to conversations on their goals.



Theme 2: A meaningful life of education, work and community participation

Meaningful experiences of education, work and community participation provide young people with the best chance of pursuing and realising their aspirations. Foundations for young people to thrive start at school and continue into adulthood as people become active members of the community and pursue further opportunities such as work. However, we found young people with intellectual disability face real challenges to and from school, work and community.

Resourcing of additional supports necessary to support the complex needs of young people with intellectual disability can be hard to come by in school, work and the community. These young people are more likely to see instances of social exclusion, potentially driven by a limited access to inclusive and accessible environments. We found they are particularly vulnerable at transitions and often lack timely pre and post school transition planning and support.

Schools, education organisations and disability services need to work together to ensure young people are provided with the supportive and inclusive environment necessary to thrive in school, work and the community. They need to have access to longer-term planning, preparation and support through transitions. And these organisations need to be adequately resourced to meet the needs of young people with intellectual disability.

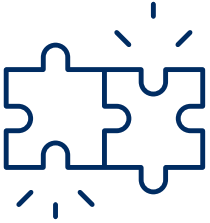


Theme 3: A secure future

Secure and stable housing is a critical aspiration and goal for many young people and carers as it is a real marker of independence. Despite advances in disability accommodation across the broader sector, we found current market conditions are sub-optimal in promoting a greater supply of suitable housing options for young people with intellectual disability.

Supports for finding appropriate accommodation supports are not always available in their preferred living arrangements. And succession planning is becoming more and more critical to ensuring continuity of supports as more people with intellectual disability start to live longer and carers age.

Organisations across the system need to work together to ensure young people have access to specialist housing and supports that provide the opportunity for independent living in their preferred living arrangements. Also, assistance with succession planning can ensure continuity of support for young people with ageing carers.



Theme 4: A robust disability service system

Readily available access to appropriate and high-quality services is critical to helping young people thrive. Service options are now a reality for many due to the early successes of the National Disability Insurance Scheme (NDIS), but there are still constraints on service choice for those requiring highly specialised supports. Planning processes fundamental to receiving funding for supports can be disjointed and the National Disability Insurance Agency (NDIA) struggles to create plans that adequately meet the complex needs of young people with intellectual disability. Pricing and allocation of supports lack the flexibility required to respond to the changing needs of these young people and there is a looming shortage of skilled staff core to supporting more complex needs. These are contributing to the real challenges with providing multiple service options necessary to allow choice and control, particularly in thin markets. We found the NDIS struggles to provide appropriate supports for young people to exercise choice and control, instead operating on the assumption that all people with disability know what is possible and available to them.

The Commonwealth Government and NDIA need to work together to ensure young people have access to responsive disability services that meet their needs and are adequately supported to exercise choice and control.



Theme 5: Healthy living

Having good physical and mental health is essential to supporting a high-quality life. Given young people with intellectual disability often have multiple and complex health needs, we need an enduring focus on supporting access to services that can provide healthcare which holistically addresses young people's needs. In our study, we found there are issues with the levels of preparedness and capacity of the health system to support young people with more complex needs, especially when it involves mental health problems. There are challenges to integrating care between health and disability services due to boundary issues and an absence of responsibility over integrated planning and support duties.

We need to work together to provide coordinated and integrated health and disability services. At the same time, strengthening the preparedness and capacity of health services and professionals is necessary to support the complex health needs of young people with intellectual disability.



Theme 6: Community attitudes

Above all, accepting intellectual disability in society is fundamental to improving outcomes for young people with intellectual disability. Through our work, negative community attitudes were frequently identified as a root cause of inequities and poor outcomes. We found a real opportunity, and an equal challenge, in combatting negative and protectionist attitudes to promote more positive narratives and encourage acceptance of young people with intellectual disability in the community.

As a society, we need to work together to promote positive community attitudes towards people with intellectual disability in society.

Introduction

Social Ventures Australia (SVA) is working towards an Australia where all people and communities thrive

While there have been positive efforts and investment from governments and the social sector over recent decades, one in four people in Australia experience disadvantage. People with disability are significantly more likely to experience exclusion and disadvantage than other groups in our community.

Since 2016, SVA has released a series of Perspective Papers in the areas of education, employment, housing, mental health, the drivers of better outcomes for First Australian people and communities, and disability.

This report is a follow up to the *SVA Perspectives: Disability* paper, launched in November 2019. It explores the experiences of young people with intellectual disability, identifies system gaps that are driving challenging experiences and opens a conversation about what is required to improve outcomes for these young people.

We hope that the included stories, insights and observations provide a foundation for the design of flexible service systems that recognise the uniqueness and diversity of this cohort and drive better outcomes for all.

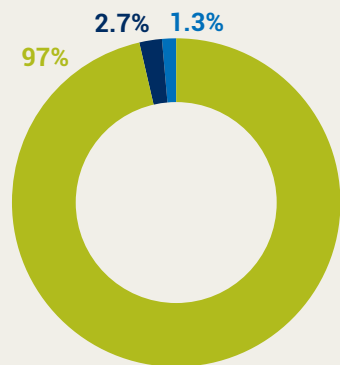
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Michelle Coulson, *Different People*, 2019

Understanding intellectual disability

More than 650,000 people across Australia have an intellectual disability, representing around 3 per cent of the population.¹ This includes around 300,000 young people.²



Australians with an intellectual disability

- Australians without an intellectual disability
- Older Australians with an intellectual disability
- Young Australians with an intellectual disability

People with intellectual disability are a diverse group and vary considerably in the nature and extent of their needs and personal circumstances.³ People will often require assistance across multiple domains of support needs and this includes⁴:



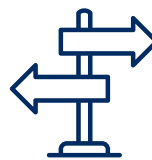
Communication

Approximately 60 per cent of people with intellectual disability require support with communication⁵ and some will have more significant or complex communication needs.



Support during times of changes

Some people with intellectual disability prefer routine and familiar environments. They may require support adjusting to changed circumstances (such as changes to support staff and programs) or when routines are disrupted. In the community, people with intellectual disability may require additional support to navigate significant change and transitions (for example, out of school and into work).



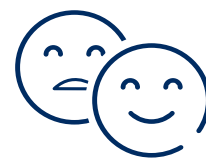
Decision making support needs

Some people may require support to make choices. They may need to have information presented in accessible formats and support people to understand their situation.



Support navigating social situations

Some people with intellectual disability may require support to navigate social situations and rules. Supports to build the capacity of community may be needed to improve attitudes and encourage greater understanding.



Complex behaviour support needs

Some people may require assistance such as positive behaviour supports to increase their quality of life and decrease severity of behaviours.

¹ ABS. 2014. 4433.0.55.003 Intellectual Disability, Australia, 2012. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4433.0.55.0032012?OpenDocument#Data> 2 ibid.

³ Australian Institute of Health and Welfare (AIHW). 2008. 'Disability in Australia: Intellectual disability.' Bulletin no. 67. Canberra: AIHW.

⁴ Centre for Developmental Disability Health Victoria. 2014. Fact sheet: Working with people with intellectual disabilities in healthcare settings. Monash University.

⁵ AIHW. 2008.

The issue

People with intellectual disability are at heightened risk of disadvantage, exclusion and inequalities compared to other Australians. These risks become greater with severity of disability, and people with significant support needs are often more vulnerable to experiencing inequities throughout their daily lives. Compared to other Australians, people with intellectual disability experience 2.5 times the number of health problems and are more likely to die of preventable causes. They are more likely to experience exclusion in school, employment and social settings, are 3 times less likely to finish Year 12 and are less likely to be in employment.

While recent reforms and investments have improved opportunities for young people with intellectual disability, more work needs to be done. In particular, many people still miss out on services critical to their quality of life, and systemic exclusion from various services and systems means many are at risk of being left behind. Research suggests challenges start at a young age and continue into adulthood, amplifying at major life transitions (e.g. to and from school and into work) that can go unsupported and impact on the foundations critical to securing better lifetime outcomes.⁷

The centrepiece of the current system is the National Disability Insurance Scheme (NDIS). This scheme provides funding for people with a permanent and significant disability for reasonable and necessary supports related to their disability. Since 2013, it has increased funding and access to supports for many Australians, enabling greater choice and control. As at June 2020, 85,000 NDIS participants (22 per cent of all participants) had intellectual disability as their primary disability group. Given comorbidities of many other participants, over 60 per cent of NDIS participants may have an intellectual disability.⁸

People with complex and high needs, including young people with intellectual disability, are also some of the largest users of disability services. And they represent a significant portion of the NDIS market by funding. At full scheme, it is estimated that 10 to 15 per cent of NDIS participants may require complex support, including some people with intellectual disability.⁹

At the same time, these young people will interact with various other support systems. Starting at diagnosis, people with intellectual disability will have multiple

engagements with the health system and continue with early intervention supports through their childhood. Most young people with intellectual disability will start their education in mainstream school settings and for some, may transition into special schools depending on their preferences and support needs. As they approach adulthood, young people with intellectual disability begin their transition out of school and into the community.

While these support services are critical to ensuring young people have equal opportunity to seek a quality of life in a direction of their choosing, the current ecosystem of supports, both disability-specific and mainstream, has significant room for improvement.

Focus of this report

This report explores the experiences of young people with intellectual disability, focusing on those with more significant support needs. It identifies system gaps that are driving challenging experiences and opens a dialogue about what is required to improve outcomes for these people. In so doing, we are seeking to elevate the perspectives and prominence of young people with intellectual disability in conversations about disability policy and service design and delivery.

The report is structured as follows:

- **Section 3** includes an overview of the methodology adopted for this research
- **Section 4** includes selected case studies of young people and their experiences of the current system
- **Section 5** includes a detailed discussion about key themes and issues impacting on young people with intellectual disability and defines priority actions to drive better outcomes
- **Section 6** sets out selected insights and observations on current experiences and system interactions resulting from Covid-19
- **Section 7** sets out selected conclusions of the research.

This document follows the recommendation from People With Disability Australia in using 'person-first' language (e.g. person with disability, rather than disabled person), but we recognise that this preference is not universal among people with disability.

⁶ Council for Intellectual Disability. 2018. *A pathway through complexity: Report from the NSW Roundtable on Meeting Complex Behaviour Support Needs in the NDIS 2017*.

⁷ Jacobs, P., MacMahon, K. & Quayle, E. 2018. 'Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis.' *Journal of Applied Research in Intellectual Disabilities*. 2018. 00:1–21. <https://doi.org/10.1111/jar.12466>

⁸ NDIA. 2020. *NDIS quarterly report to the Ministers: 20 June 2020*.

⁹ Summer Foundation. 2018. 'New complex support needs pathway'. <https://www.summerfoundation.org.au/new-complex-support-needs-pathway/>

Methodology

The central focus of this report is to better understand the experiences of young people with intellectual disability, specifically those with more significant support needs.

In undertaking the research, we wanted to learn more about young people's hopes and aspirations for the future. We also wanted to learn more about their experiences of education, work and community, including how they influence the achievement of these aspirations. And we wanted to learn more about opportunities to drive better outcomes in the future.

We adopted various methods to examine these issues – anchored in understanding the experiences of young people with intellectual disability as well as challenges and opportunities across the system.

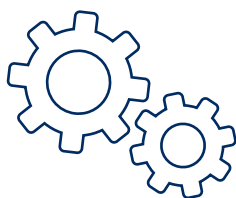


1. Conversations with young people and their carers

In partnership with Today Strategic Design, we had conversations with young people and carers about their lives and experiences. These conversations included young people from across different age groups, genders, geographies and cultural backgrounds.

The stories of these young people are included throughout the report. They have been told and shared by carers with select contributions from the young people themselves. While we recognise this builds understandings about past and current experiences, we also appreciate this is a limitation of our work.

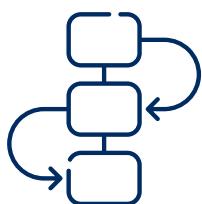
Ongoing work is required to better capture the voices of young people directly.



2. Understanding sector perspectives

Building on our conversations with young people and carers, we identified six themes that had a particular impact and influence on young people's experiences. Across each of these themes, we completed a targeted review of available research, position papers and government policy documents to understand how the system works overall to support positive outcomes for young people with intellectual disability and to identify system gaps that drive negative outcomes.

In parallel, we interviewed service and sector leaders to hear their perspectives on the most pressing challenges and opportunities across the system. This included interviews with leaders from peak bodies and support services, as well as academic researchers and disability advocates.



3. Proposing future priorities

We synthesised what we heard through our conversations and desktop research to draw linkages with the identified challenges faced by young people. Within each theme, we identified opportunities for system players to work differently so that they can more effectively support young people with intellectual disability.



Stories of people with intellectual disability

Three stories of young people with intellectual disability are included below. These stories were told to us by carers with select contributions from young people themselves.

They provide a window into the experiences, needs and aspirations of the young people.

Stories of a further eight young people are included in the next section of the report and provide broader perspectives of current experiences.

Case Study 1: Connor and David

Connor (36) lives in supported accommodation with his brother and three other residents. Connor has become well known for his art and photography in his community, with some people showing interest in purchasing his work. He also loves cars, his friends and spending time on his iPad. Connor had a seizure after he was born and has a moderate intellectual disability.

David, Connor's legal guardian, started as a care worker for Connor. He has known Connor for 21 years. David is actively involved in Connor's life, supporting Connor with his affairs and spending time with him regularly, including during holidays and fortnightly sleepovers.

Making choices

Making good choices can be difficult for Connor. While Connor is encouraged to make his own decisions, he needs support to understand and work through the circumstances that surround a choice. David encourages Connor to think about the implications of his actions, especially if they are abstract or not immediate.

The question of choice is a source of conflict between Connor, David and the supported accommodation staff. From David's perspective, Connor is given freedom to make decisions without the support he needs to make good choices.

Some of the decisions Connor makes without guidelines involve food and exercise. He has put on a significant amount of weight since moving into the house, and David is concerned that this is because he doesn't have the support he needs to understand his choices.

"I think the thing with food is that it's an impulse control thing, and he can't control it."

David believes Connor needs boundaries so that he can participate and make progress, while Connor and his support worker feel he should be free to do as he chooses.

David believes Connor benefits from being with other people who can act as role models and teach him new things.

Connor has wanted to try many activities, including tennis and basketball, that turned out to be a lot more difficult (and less enjoyable) than he imagined.

"I can explain to him, 'These are the consequences. This is what will happen. These are some possibilities.' He'll say 'Yeah, yeah, yeah'. Then when it happens, he goes, 'Oh'. And I go, 'Look, that's what I told you was going to happen.' 'Oh, well I don't like this.' I tried to explain."

It's also important for services to understand Connor's likes and dislikes. In the past, when Connor has been put in a program he doesn't want to be in, he has reacted accordingly.

"They were giving him things that he didn't even have an interest in and then complaining that he's not behaving. Of course he's misbehaving! You're giving him stuff he doesn't want to do. He's already said he doesn't want to do it."

It wasn't until there was a threat of Connor's NDIS funding being pulled with one provider that Connor was given access to the options he wanted.

Learning new skills

Connor thought that moving into supported accommodation would be a party every night and that he wouldn't have to go to work. When he found this wasn't the case, he wanted to move back home. Connor finds the rules hard to cope with, especially getting up in the morning and completing chores.

Connor was once removed from an arts program he attended when he went missing and was found in the kitchen drinking champagne. It was a difficult time for Connor after his Mum passed away. At that time he would have benefitted from more support and guidance. He didn't have a support worker with him at the program.

David believes Connor benefits from being with other people who can act as role models and teach him new things.

"What's been unfortunate for him is that he's been put in groups where he may be the one with the loudest voice and he leads others astray. If they had someone with a louder voice, above him, then he'd go, 'Oh, that's who I want to be like!'"

David is critical of low expectations for individuals living in supported accommodation. He's eager to see Connor progress and move out but worries that he doesn't have the support to develop the skills to manage it.

Unfortunately, Connor's skills have decreased since moving into supported accommodation. This includes his handwriting, reading and independence skills like cooking and cleaning. Rather than teaching Connor how to do these things for himself, staff tend to do things for him.

"The staff in the house don't like [Connor] following them around when they're doing jobs. I've said to them, 'Ask him to help you, then you'll get the job done quicker.' They reply 'Sometimes it's easier to do it on your own!'"

Connor is compassionate and caring but can misinterpret social cues. He might say something meant to be funny and sarcastic, but it can come across as rude. Connor often won't know why he has offended the other person. He has begun building social skills with a psychologist, which has been beneficial for his development.

Finding and keeping a job

Connor has had a number of jobs but struggled to stay in work. This has often been due to a lack of understanding and support for Connor's behaviour support needs, leading to him either losing motivation or being seen as a negative influence on his peers. For example, Connor lost his job at a cafe after he 'led a revolt' because he didn't like the pants they had to wear as part of the uniform.

"They lost half their staff because Connor was telling them 'Don't wear your uniform.' And then he started running up and down the hallways, yelling at people."

When David asked Connor why he acted that way, he couldn't explain.

"I don't know. I probably wasn't thinking straight."

Connor then started an unpaid trial period with a hardware store, with the aim of converting it into paid work as Connor's skills picked up. Connor was excited about this opportunity at first but he struggled to stay engaged.

"He didn't want to [do the work], like with his reading and writing, he would always complain, 'I don't want to do this.' I'd say, 'Do you want to come outside and help me mow the grass?' 'No, I don't want to,' he'd reply."

Connor says he'd like to work with elderly people in an aged care home. He imagines being able to talk to them and play games with them.

Connor also had a temporary unpaid role at an arts program he'd been attending for 10 years. When he became bored at the program, staff gave him a job setting places for people to sit. Connor then took that as him 'being a worker' and he was confused about why he wasn't getting paid. There were some incidents where Connor got into an argument with some people for coming in too early and the role didn't continue.

Now Connor says he'd like to work with elderly people in an aged care home. He imagines being able to talk to them and play games with them.

Living independently

When asked about his goals, Connor talks about moving out and getting his own space with a housemate and a dishwasher. He likes this idea because he sees it as a way to spend more time with his friends.

"I like to have my own space, because then I can invite my friends over any time."

From David's perspective, there are a number of things he thinks Connor will need to have in place before he moves out on his own, including learning how to wash, clean and cook, and start working to earn the money for rent.

Case Study 2: Nathan and Jodie

Nathan (25) lives with his mother, Jodie, and is an only child. He spends a lot of his time with friends and can be very chatty. Nathan has severe cerebral palsy and uses a wheelchair. Despite his capabilities, he has been assessed as having low cognitive ability. He can remember names, navigate to familiar places and communicate with others. Jodie describes Nathan as 'very social and resilient'.

Nathan and Jodie live in a house in a northern Melbourne suburb.

Challenging assumptions

Nathan's abilities are hard to categorise and are often overestimated due to his good social skills. This can lead to misdirected expectations, which often happened with teachers during primary school.

Nathan's abilities are also often misunderstood by strangers because he's good at small talk and routine tasks like ordering food or visiting his GP. But at times Nathan can be quiet, and this can lead to misunderstandings.

Jodie felt that the expectations placed on people with intellectual disability and their families were unrealistically high.

"Some days you can have a fantastic conversation with him and he'll give you full consciousness. He made the speech at his graduation! But then other days, like today, you can't get an answer out of him."

Going to school

When Nathan was young, he attended both a mainstream and a special school. Nathan's experience at school often depended on the teacher aide who was with him and how well they understood his needs.

Teachers overestimated his actions, attention span and patience, which meant they would often get frustrated. Unfortunately, approaches to supporting his complex

needs were often inconsistent and based on assumptions about Nathan's abilities. For example, one of his aides would leave him in the corridor outside the classroom as punishment for misbehaving. This was ineffective as Nathan didn't understand that he was misbehaving.

"If Nathan reached out and grabbed anyone or was distracting somebody during schoolwork, she'd stick him outside the classroom as punishment, as time-out. Nathan thought that was ridiculous, a joke. He had no concept of it at all."

The mainstream school was better for Nathan from a social perspective, as there were fewer opportunities for him to make friends at the special school. For example, when Nathan and another boy wanted to be friends, the school wasn't able to facilitate the friendship because of the way classes were structured. Nathan was told he and the other boy couldn't be in the same class because they had a similar level of need, even though placing them in the same class would have allowed Nathan to build a new friendship.

"I'd go down and say, 'Can they be in the same class?' [They said] 'No. We've got to balance up the needs of the children.' I felt the school could have done more to facilitate friendships among people going to the school."

Transitioning out of school

As Nathan approached his 18th birthday and prepared to transition out of school, Jodie grew concerned about the amount of support they were receiving to navigate this major life change.

"They need to be more of a help than that. It's the transition into adulthood that sometimes gets misunderstood. For every young adult that I know, the transition to adulthood hasn't been 18. It's been more like 22."

Jodie felt that the expectations placed on people with intellectual disability and their families were unrealistically high.

"The responsibility that they're putting on young people with disabilities at the moment, with the choice of control... tension is incredibly high. They're even encouraging you to do self-management for your NDIS claim."

This often places greater responsibility on the primary carer to do all the coordination.

"And it falls more back onto a parent to coordinate what's going on. So you're having to be the link between everybody."

Navigating adult services

As an adult, Nathan's actions continue to be misinterpreted. At his day program, the carers seem to confuse his expression of boredom with intentional misbehaviour. Jodie worries that Nathan's experience is due to carers making assumptions about him and not having the time and energy to understand him.

"The challenge is that he's bored out of his brain at programs. And I believe as a result of that boredom, he will grab people."

Those who know Nathan recognise that his actions come from a positive place.

"They're actually starting to write up incident reports... but it's not the criminal offence they make it out to be. Because I'll ask him why and he'll give me a reason like 'I thought that someone's drink was going to fall' or 'I wanted to say hello' or 'That worker wasn't listening to me'."

Nathan has a positive experience when carers treat him more as a friend, respecting his wants and needs.

"When it's worked well they've struck up more of a 'friendship' approach with Nathan. It's still professional, but they wanted to know what his goals are and what we're trying to instill or develop. As opposed to that, we've had workers who said 'Isn't Nathan cute?' And treat him baby-like, and he just dismisses them."

Adjusting to adult services has been difficult because of the loss of continuity between services. It feels fragmented compared with children's services.

"Once you leave the Children's [Hospital] it's spread everywhere... You go to a day program, the day program isn't watching you. You're not getting the intensive support they have at a special school."

There is less of a holistic picture of needs and connecting the dots between the things that could increase wellbeing.

"It's very much towards what equipment and what physical needs they have. 'Let's measure his scoliosis', 'Let's look at some treatments that can make him straight' rather than 'So, let's get him into a wheelchair basketball team'."

Jodie thinks there's a gap in the transition to adult services for people with cerebral palsy because the growing demand for adult services only emerged in recent years as a result of increased lifespans.

Adjusting to adult services has been difficult because of the loss of continuity between services. It feels fragmented compared with children's services.

Planning for the future

Nathan's goal is to move into his own house one day with friends. Nathan already spends a lot of time in respite homes, so he's used to spending time away from Jodie. He also has a strong network of friends that Jodie has helped facilitate throughout the years. Along with his friends' families, they have built a good support system that can enable his independence in the future.

"I'd like to see him settled in his house with some supports around him who'll ensure his interests are protected and who'll continue to ask him what he wants. I want to give families hope that even if their child [has severe disability] and can't work, they can be happy."

Case Study 3: Katherine and Lisa

Katherine (24) lives independently in supported accommodation, which she shares with one other person. She moved out of her family home two years ago.

Katherine is an inquisitive person with a quirky sense of humour, who likes to have control of her environment. She enjoys swimming, art and being in the outdoors – especially the beach. Katherine has a moderate intellectual disability, autism and generalised anxiety.

Lisa is Katherine's mother. While Katherine has moved out of home, Lisa continues to play an active role in Katherine's life by managing her NDIS plan and most of her supports.

Having complex support needs

Some of Katherine's actions may come across as surprising to those who don't know her.

"She'll go through people's belongings. If someone turns up with a handbag, Katherine will start going through the handbag. She might find a lolly or a chocolate if she's lucky."

Katherine enjoys controlling her environment and needs to control the kitchen and what's in her room. Lisa explained that Katherine is often decisive about her preferences in the moment.

"If she decides that she wants to do something, she'll do it."

Other times, Katherine's actions can escalate.

"She can be a challenge... she can become quite angry if she gets very stressed."

Katherine's behaviour support needs are sometimes misunderstood by her support workers. Staff who know her are familiar with her anxiety and how it can lead to her actions, but new staff have difficulty understanding.

As she's become older, her actions have become more problematic. She sometimes doesn't like people in her space, and some things that happen in the environment can send her into a bit of a panic. If she gets upset, Lisa and her support workers will use a range of different approaches such as music and other sensory tools to help her to keep calm.

Katherine attends her day program five days a week. Lisa describes the program as being supportive and inclusive in the way staff work with Katherine and people with more complex needs.

Participating in the community

While Katherine enjoys the outdoors and being in the community, it hasn't always been easy for her to feel comfortable around other people. Lisa has been trying to use different strategies to get Katherine out and about. The main challenge is people coming into her space. While she does go out occasionally, she finds crowded places overwhelming.

"She was at the beach with one of the carers. A child came screaming in front of her. She ran to the carer and started pulling the carer's hair."

Katherine attends her day program five days a week. Lisa describes the program as being supportive and inclusive in the way staff work with Katherine and people with more complex needs. Lisa believes that without the program, Katherine wouldn't have many other opportunities to participate in the community.

"There weren't any other services that designed programs around her rather than have her fit into what they do, which is usually having a bus full of people doing activities together. Being able to have greater control over what she does means she has fewer issues with her situation. They also have OTs and speechies who are brought in to put strategies in place so she can interact as much as possible."

Katherine can find change difficult. So program staff will go through her week with her, asking who she's seeing on Monday, where she's going and what she's doing. If they see change coming, like new staff or activities, Katherine is provided with as much notice as possible.

"We have a system where we message the program, and they tell us who she's with and who's picking her up. Sometimes they come to the house. She sits in the back and they drive her around. She doesn't really like other people in the car with her."

Feeling healthy and well

Katherine and her psychiatrist have been trying different medications over the years to help with her anxiety and behaviour support needs, but none of them have lasted very long.

"It's always a trial and error thing with any medication. Sometimes they cause more problems than they solve... You hear reports that say you give them this and they're fixed but that's not true for her. It might work for a little while, but then it stops and there are all these side effects. We're forever looking at different options."

Over the last few years, Katherine has been getting better with her anxiety and her psychiatrist has been trying to get her off a lot of the medication. Lisa is hoping that the current mix of medication will help Katherine with her anxiety so she can start to get the most out of her life.

They are now working on building a new house that's close to the family and her day program. The house will be designed to ensure Katherine and her housemate have their own self-contained units with shared spaces where they can have BBQs together with staff and families.

Living independently

Katherine currently lives independently with a housemate in a rental property that has been renovated and adjusted. Prior to the current living arrangement, Lisa navigated challenges in applying for funding for services. Katherine's initial application for funding to support her to live alone was rejected. She could only get funding for independent living services by living with somebody else.

"Trying to find Katherine a suitable roommate is next to impossible. Finding someone who does what she says, sits where she wants them to sit, gives her whatever she wants – that's what she needs. But it's not really practical."

Lisa found someone who was looking for somewhere to live. Even though they knew that compatibility would be an issue, they gave it a shot to provide Katherine with the opportunity to live independently. The other woman moved in for two or three weeks but quickly realised that the arrangement wouldn't work.

"Katherine was just getting increasingly agitated, so we had to stop the arrangement and look for another appropriate rental place... I knew that it wasn't going to work. But that was what we had to do to get the funding. It felt a bit dishonest."

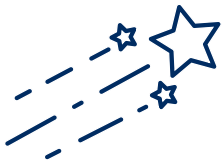
They are now working on building a new house that's close to the family and her day program. The house will be designed to ensure Katherine and her housemate have their own self-contained units with shared spaces where they can have BBQs together with staff and families.

Lisa also wants to put in a pool for Katherine because she loves swimming.

"Most providers don't allow pools because they see it as a risk. But we don't see it as a risk because she's a good swimmer. That lets her have a lifestyle at home instead of going to public places where she can get stressed out by other people."

Discussion

Through our conversations with young people and their carers alongside our work defining sector perspectives, six themes were identified as key influences on the experiences of young people with intellectual disability.



Rich and diverse aspirations:

Young people with intellectual disability have rich, interesting and varied aspirations for the future. Supporting young people to realise these aspirations is an enduring goal for carers and families and needs to be a central focus of the service system.



A meaningful life of education, work and community participation:

Meaningful experiences of education, work and community participation provide young people with the best chance to pursue and realise their aspirations. For some young people, access to these experiences is already a reality, but for many others current experiences fall well short of the ideal. Addressing current challenges and gaps must be a key priority across the system.

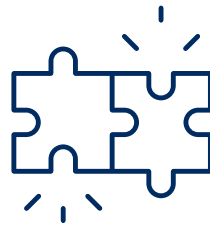


Plans for a secure and stable future:

Secure and stable housing represents a critical aspiration and goal for many young people and carers as it is a real marker of independence. But despite advances in disability accommodation, there is still a pressing need to focus efforts to boost the provision of appropriate and varied accommodation supports for young people with intellectual disability.

These themes represent a mix of systems, behaviours and drivers that collectively shape the make-up and quality of life of a young person with intellectual disability.

A description of each theme is included below. The following sections provide an outline of key observations, insights and priority actions across the themes.



A robust disability service system:

Ready access to appropriate and high-quality support services is critical to helping young people thrive and pursue their hopes and aspirations. Service option is now a reality for many due to the NDIS, but there are still real constraints on service choice for those requiring highly specialised supports.



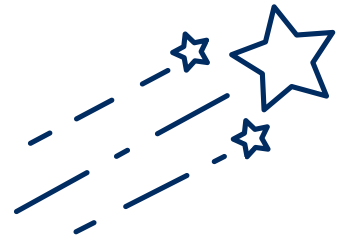
Healthy living:

Having good physical and mental health is critical to supporting high quality of life. Given young people with intellectual disability often have multiple and complex health requirements, there needs to be a focus on supporting access to services that can provide healthcare which holistically addresses young people's needs.



Positive community attitudes:

Above all, accepting intellectual disability in society is fundamental to improving outcomes for young people with intellectual disability. Through our work, negative community attitudes were frequently identified as a root cause of inequities and poor outcomes. A sustained focus on community attitudes to shift the paradigm for young people and open a new world of opportunities is required.



Theme 1: Rich and diverse aspirations

Across our conversations with young people and carers, review of evidence and interviews with systems actors, we found a strong link between rich and diverse aspirations of young people and quality of life. In particular, we found that there is a shared hope and vision for young people from across the system – a vision where young people pursue a life of meaning and one of their choosing. This starts with placing the person at the centre and recognising their agency when supporting them to achieve this vision.

Setting and pursuing aspirations and goals¹⁰

Young people should all have the chance to pursue lives of their choosing – lives that are rich with opportunities to learn, work, connect with others, and engage in and with their community. And this should not be different for young people with intellectual disability.

Having well defined aspirations and high expectations can provide young people and carers with purpose and confidence to take control over decisions and pursue lives of their choosing. Through our conversations with young people and carers, we found a rich diversity in aspirations unique to each individual: aspirations to engage with family and friends; aspirations to engage in the community; aspirations to live independently or with friends; and aspirations to learn and engage meaningfully in work.

Importantly, supporting young people to define, pursue and realise their aspirations is an ongoing objective for carers, families and advocates and needs to represent a core focus of any service or individual supporting young people with intellectual disability.

At a system level, the National Disability Insurance Scheme Act 2013 (NDIS Act) requires all support plans to include a participant's statement of goals that must be considered when making decisions on support.

This means goals are central to discussions between services and young people to ensure funding is targeted to areas aligned with their aspirations. And real action and progress is understood as being made in this area. Yet a recent study by the University of Melbourne found that, for some participants, this link between supports and goals is not always clear.¹¹ For instance, young people with intellectual disability can have complex communication barriers that impact on their ability to self-advocate or voice concerns. And without appropriate supports to offer

them opportunities to share their perspectives, these young people can be vulnerable to inappropriate and unfounded assumptions about their preferences and priorities. We also found disconnects extend beyond recognition to the allocation of funding and supports in the system. For instance, the NDIS focus on self-management and employment can create tensions for young people who are not able to self-manage personal finances or build the soft and/or hard skills required for employment.

More broadly, there is a difficult balancing act between ensuring dignity, risk and duty of care. As a cohort with high support needs, risk reduction approaches are often favoured by service providers, prioritising duty of care over a young person's right to take on risk through their choices. From a provider's perspective, we found it is not always clear what the optimal balance looks like as capabilities and support needs can be hard to judge. And without the right supports surrounding young people or guidance for services on best practice methods of engagement, young people with intellectual disability can be prevented from their right to choice and control. Carers highlighted the lack of connections to role models or relatable stories of young people in the community as contributing to the uncertainty.

Carers will have their own aspirations for the young person in their care. These aspirations may be complementary, reinforcing a young person's own vision. They can also differ and tension arises when decisions are made without appropriately acknowledging a young person's own preferences¹².

Future directions

Well-defined goals

Having well defined goals for young people ensures service providers are clear on potential and available services that will help young people thrive. Having meaningful input from young people themselves on the formation of these goals is a critical feature of setting such a vision. Yet it is important to recognise this is not always a straightforward process and that the input and perspectives of carers may also be considered. Providing services with guidelines on best practice approaches to navigating this area could help to address confusion and mixed practices about appropriate expectations, particularly as they relate to the formation of NDIS support plans and packages.

¹⁰ For the purpose of this report, 'aspirations' is used throughout the report to refer to a young person's short to long term ambitions, while 'goals' is used to refer to the statement of what a young person would like to achieve with support from the NDIS.

¹¹ Warr, D., Dickinson, H., Olney, S., et al. 2017. *Choice, control and the NDIS*. Melbourne: University of Melbourne.

¹² Notably, carers may have aspirations for their own futures that cover a range of areas including professional and personal pursuits. These pursuits need to be considered alongside caring responsibilities, with challenging decisions often being made that results in prioritising one area over another. This is a significant issue that deserves its own attention separate to the focus of this report.

Appropriate methods of communication and engagement need to be provided to ensure young people are given genuine opportunity to have a voice in decisions that impact on their ability to set goals and pursue their aspirations. Aspirations are changing and require ongoing dialogue and discussion to ensure the best possible outcomes.

Knowing what is possible

We also found that, while there is increasing recognition of the importance of understanding and pursuing aspirations,

Case study 4: Shaun and Maddy

Shaun (10) lives with his mother Maddy and four siblings at their family home in outer Melbourne. He is the youngest of the five children. Shaun loves swimming, playing ball sports and making pancakes. Maddy says Shaun is a bright and friendly child who's often underestimated by other people. Shaun has a significant intellectual disability. He needs some support to communicate and is learning how to sign.

Knowing what's possible

Maddy was a 'deer in the headlights' for the first five years with Shaun. She describes the experience as a learning curve and talks about spending hours on the internet researching and learning about Shaun's capabilities.

Online forums with other parents were a lifeline, offering a non-judgmental space where Maddy could learn from others with similar experiences.

Maddy is unsure about what the future holds. She hopes that Shaun's abilities will continue to grow and develop, and that he'll get a job and be able to look after himself. But she concedes that Shaun's future is unclear and depends to some extent on how his communication skills develop. Maddy says she's been thinking about this a lot recently, after her eldest daughter asked her what would happen after she dies. She's concerned about the prospect that Shaun might end up in an aged care facility.

there is real variation in understandings about what is possible. For instance, carers highlighted the need to better understand potential pathways and prospects for young people in their care. And in instances where specific pathways are being promoted, there needs to be assurance that they are readily available in the young person's community.

They also highlighted the need for identifying and connecting young people to role models to ensure there is a clear picture and example of the directions and pathways that young people might pursue. There is an opportunity to share more information about potential pathways and meaningful stories that young people and carers can relate to.

We also heard that, while the goal driven framework of the NDIS works for most, it does not always suit the realities of those young people with high support needs. More clarity on how principles such as independence and choice apply to people with intellectual disability is needed to ensure carers and providers have better information and guidance on what good outcomes look like for all young people.

Priority actions

- National Disability Insurance Agency (NDIA) and disability service providers to work closely with young people with intellectual disability and carers to agree on common understandings and approaches to setting and pursuing goals and incorporating them into their supports. This includes providing guidance to services on best practice approaches to engaging young people with intellectual disability in conversations on goal setting and ensuring appropriate supports are provided to make sure that all voices can be heard.
- Commonwealth Government and disability and community service providers to work closely with young people and their carers to share and promote different pathways for young people and to examine potential opportunities to better link young people with role models across the community.



Theme 2: A meaningful life of education, work and community participation

Education, work and community engagement are hallmarks of everyday life in modern Australia. They provide young people with a platform for community and economic participation. While young people with intellectual disability will have varying experiences of education and employment, the opportunity to participate in these central parts of modern life is important to wellbeing and social inclusion.

Critical foundations for young people to thrive start in the schooling years, where they build capabilities to engage in and with the broader community and form social connections and friendships. From school, many young people are set up to pursue employment. Others pursue community participation and engagement pathways. Our study identified real challenges faced by young people at the end of the schooling years and in the transition to adulthood. Many young people and carers are confronted by the challenge of understanding and navigating a complex network of opportunities, services and pathways.

Foundations for inclusion

Schools are a springboard for all young people to flourish. In a school setting, inclusive education practices are integral to ensuring young people with intellectual disability can participate in learning as well as form meaningful relationships with their peers. Across the country, schooling systems have a range of policies and practices in place that promote the inclusion of students with intellectual disability into mainstream school settings. Many start their education in a mainstream school, with special schools also available should these options be more suitable.

Under the current system, it is assumed that young people and carers have the choice and opportunity to select the schooling option that best supports their context and needs. This approach is supported by a growing body of evidence that highlights the positive impact that inclusive education can have on the academic, social and emotional development of students with intellectual disability, as well improved social outcomes for their peers.¹³ Yet a survey by Children and Young People with Disability found that 12 per cent of children with a disability had been refused enrolment in mainstream schools.¹⁴

This highlights the potential use of informal gatekeeping practices and raising questions about the extent to which true choice is provided. We heard from carers that, while mainstream schools are prepared to support young people with intellectual disability in the early years of school, many are encouraged to transition into special classes or schools as they get older.

Young people with intellectual disability are more vulnerable to experiences of exclusion at mainstream schools. For instance, one in five Australians still feel uncomfortable having their child share classrooms with young people with intellectual disability.¹⁵ Young people with intellectual disability are more likely to experience bullying and be excluded from school activities such as excursions.¹⁶ In addition, one in three young people with disability experience restrictive practices in the form of restraint or seclusion.¹⁷

We found strong consensus among education leaders on the need for greater support and resourcing of mainstream schools to build their capacity to deliver more inclusive approaches and models of teaching and learning. This includes guidance on when external supports (e.g. therapeutic care) should or should not be allowed on school premises.¹⁸

Future directions

An inclusive education system

The growing body of evidence showing the benefits of inclusive schooling¹⁹ indicates there is a strong case for providing more young people with access to inclusive education in mainstream schools. Importantly, there was strong support among education leaders, families and carers consulted in the current study for having a more inclusive system for all young people, including those with intellectual disability.

To prioritise and progress the conversation in Australia, there is a need to build on existing understandings and practices. This could involve educators, service leaders, government and carers coming together to discuss current experiences alongside the benefits and opportunities for advancing a more inclusive system. This type of dialogue could help grow the coalition of informed advocates, with

¹³ Cologon, K. 2019 *Towards inclusive education: A necessary process of transformation*. Macquarie University for Children and Young People with Disability Australia (CYDA).

¹⁴ CYDA. 2019. *Time for change: The state of play for inclusion of students with disability – results from the 2019 CYDA National Education Survey*.

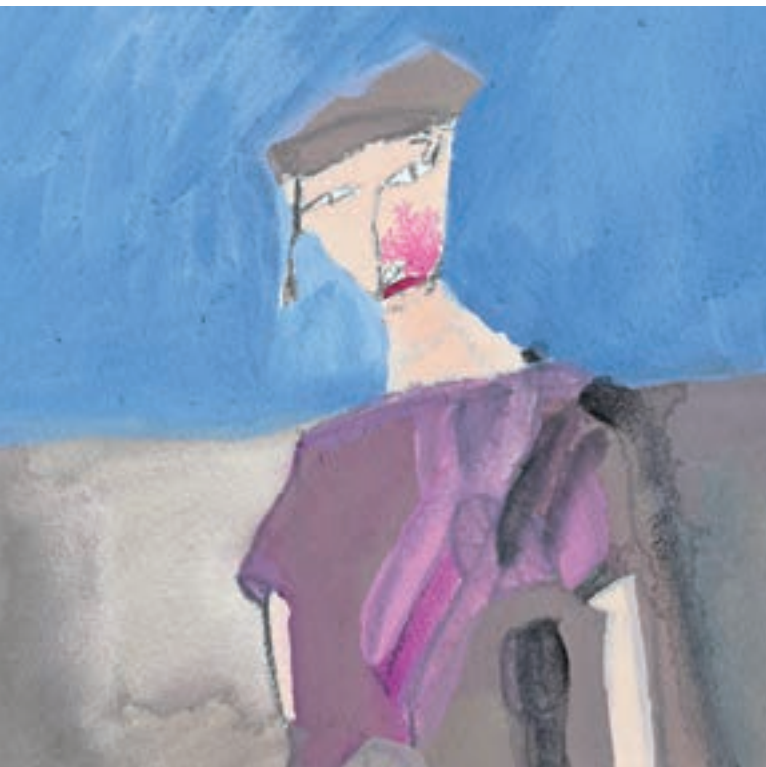
¹⁵ Michael, L. 2020. 'Aussies 'uncomfortable' with students with intellectual disability in their child's school.' Probono Australia. February. <https://probonoaustralia.com.au/news/2020/02/aussie-parents-uncomfortable-with-students-with-intellectual-disability-in-their-childs-school/>

¹⁶ CYDA. 2019.

¹⁷ *ibid.*

¹⁸ Commonwealth of Australia. 2018. *Transitional arrangements for the NDIS. Joint Standing Committee*. ISBN: 978-1-76010-706-2.

¹⁹ Cologon, K. 2019.



Paul Hodges, *Not titled*, 2019

the aim of encouraging school leaders and education policymakers to prioritise support and resources for young people with intellectual disability.

Building an evidence base

To promote a greater uptake of inclusive practices, education leaders highlighted a need for greater documentation and dissemination of effective and practical strategies for mainstream schools to support young people with intellectual disability.

Building and sharing a practical evidence base for inclusive education in Australia should include developing clear and consistent definitions of inclusion and related concepts; capturing what schools are doing to successfully support young people, including classroom instruction and integrated supports; researching how and why schools successfully implement inclusive education practices; and implementing robust data collection methods to identify the most effective approaches and validate the benefits of inclusive education. It could also involve building on the work of existing initiatives such as inclusionED, an online professional learning community that is a collaboration between Autism CRC and Queensland University of Technology, which provides free evidence-based teaching practices and tools to support diverse learners in inclusive classrooms.²⁰

²⁰ inclusionED. 2020. About. <https://www.inclusioned.edu.au/about>

²¹ Davis, K. & Henderson, P. 2020. *Special education needs in mainstream schools*. Education Endowment Foundation.

²² Cologon, K. 2019.

²³ Commonwealth of Australia. 2018.

The creation and dissemination of this type of evidence could help to increase confidence among educators and policymakers on inclusive education practices. It could also help carers when making decisions about schooling, to ensure that they are informed about the benefits of different schooling options.

Capable mainstream schools

Schools need to build universally accessible learning environments and teaching strategies that provide supportive learning environments. This includes using modified curriculum and multi-modal communication tools, and providing ongoing support for teachers.

Access to effective professional development for educators is important in building the capacity of schools to effectively support young people with intellectual disability. A recent global evidence review – *Special Education Needs in Mainstream Schools* – found that supporting students with complex needs in mainstream schools should involve creating a positive and supportive environment for all students; building an ongoing, holistic understanding of students and their needs; complementing high-quality teaching with carefully selected small-group and one-to-one interventions; and working effectively with teaching assistants.²¹ This program of work represents a significant undertaking and mainstream schools need targeted support and funding to build their capacity and capability to do this effectively.²²

There is an ongoing need for greater guidance to schools and support providers on how to navigate the boundary between the NDIS and education systems to ensure integrated supports can be provided to young people in a school setting in a way that enables them to participate alongside their peers.²³

Post school transitions

Transitioning out of school and into the community is a critical time for a young person with intellectual disability. The completion of school represents a major milestone and achievement for young people and their carers, marking the end of a learning journey and a key chapter of life. It also creates a new and complex set of challenges.

Daily routines, participation in employment or further education, engagement in community activities and connections to adult disability and health supports all become the responsibility of young people and their carers. And young people need to learn how to participate in and across the community as mature adults.

Enabling an effective a transition out of school is critical to supporting a young person's wellbeing. But post school transitions have been found to be particularly difficult for young people with intellectual disability.²⁴

Our conversations with carers highlighted the process as being one of extreme stress and challenge.

Carers noted how the transition represents an abrupt departure from the strong social foundation and platform provided through school. In its place, carers and young people are given the task of stewarding this significant change alone. Limited support for planning, fragmentation of the adult support system and limited post school options make transition experiences particularly hard.

A specific challenge is that current post school options largely focus on pathways that target those who require less support and are not always relevant for young people with intellectual disability. Our conversations with carers and interviews with disability employment services revealed that many existing pathways underestimate the potential of young people with intellectual disability, creating barriers to pursuing employment and other destinations. As a result, young people are often forced to transition into community-based programs before genuinely exploring other options. This is exacerbated by unclear responsibilities between education and employment services at the school to work boundary, preventing continuity of support through the transition.²⁵ Not surprisingly, a 2012 inquiry into transition support for students with complex needs and their families in NSW found that post school planning happens ad-hoc and often too late, and in some cases not at all.²⁶

Future directions

Coordinated transitions

It is clear that successful transitions out of school play a significant role in ensuring young people are supported into meaningful pathways. And it is clear that current

Case study 5: Pete and Steph

Pete (28) lives with his sister Steph and her family. Steph became Pete's primary carer just over a year ago. She describes Pete as 'trusting and cheeky'. Steph says her brother can be mischievous at times, especially when he's playing tricks on his young nieces. Pete has an intellectual disability and has communication and physical support needs.

Transitioning from school

Going from the routine of school to being at home was a significant transition for Pete and his family. The family felt let down by the lack of support from Pete's school, which didn't help them find providers who could help continue his skill development. Although Pete's parents could support him with daily tasks, they struggled to organise a new routine that would enable Pete to continue to build skills. Steph then began to liaise with local providers to find out more about his options.

Pete himself found this transition time quite distressing due to the sudden change. Knowing this now, Steph tries to make sure big changes to his routine are introduced slowly so that Pete feels comfortable.

"If it's a major change, it takes quite a while for him to come to terms with it. He becomes frustrated, he can get quite upset. He just needs that constant reassurance that it's going to be alright. It's got to be introduced gradually and slowly, not suddenly."

Pete's family hopes he can become more confident in daily activities, including preparing his own meals. These practical activities are the critical skills Pete needs to build independence. Steph recognises the improvements in support that resulted from the introduction of the NDIS but would like to see Pete receive more formal support to build these essential life skills.

²⁴ CYDA. 2015. *Post school transition: The experiences of students with disability*.

²⁵ CYDA. 2015.

²⁶ New South Wales Parliament. 2012. *Transition support for students with additional or complex needs and their families* (Report no. 45). Sydney: Standing Committee on Social Issues, Parliament of New South Wales.

processes are not working for all. There is a need and opportunity to enhance the focus and availability of transition planning and preparation. There is also a need for better coordination and clarification of responsibilities between education providers, employers and other services to remove frictions faced by people moving between these systems when they first leave school.

Supported transition programs

In our interviews with education and employment leaders, we were told of the need to build awareness and access to effective transition programs to ensure more young people are able to pursue work-related and employment pathways. In particular, conversations regarding a young person's employment prospects need to commence early and be supported by long-term career planning.

Through our study we found that initiatives which support young people through the transition from school to work, such as School Leaver Employment Services funded under the NDIS, are seeing promising results, noting more evidence on long-term outcomes is required to fully understand their effectiveness.

Pathways out of school

Determining the right pathway for a young person with intellectual disability is complex. It can be a difficult task to understand a young person's aspiration and to find the right option that fits within that vision. One challenge in this process is that many pathways are simply not understood or known.

There is a need to provide young people and carers with better information and resources that outline potential post school options. Importantly, young people need to be provided with greater clarity on pathways that matched to their aspirations.

Finding and keeping a job

The opportunity to work in stable employment for young people is linked with improved health and wellbeing, and social, economic, and financial inclusion.²⁷

Employment has increasingly become a core policy priority for people with disability in Australia, where the economic case for the NDIS is underpinned by having more people in employment. Yet while the opportunity for employment is an option for many, it is not the case for all and will ultimately depend on an individual's capacity, support needs and aspirations.

Nationally, the employment rate for people with disability is much lower than that of other Australians²⁸ and lower than the OECD average on equivalent measures.²⁹

Current options for young people with intellectual disability include three prominent pathways.

Open employment represents one pathway, with better pay and social inclusion outcomes compared to some alternative options. However, we found young people with intellectual disability face barriers to accessing and maintaining work in the open market, including insecure or irregular employment terms and discrimination from co-workers.³⁰

We also found that many current barriers stem from a lack of support for employers to build their capacity and workplace culture to support more people with intellectual disability to maintain employment. Also, the availability of jobs suitable for young people with intellectual disability is limited. An analysis on the job market conducted in May 2020 indicates that on average, 106 jobseekers are competing for every entry-level position³¹ – positions many of these young people are seeking in the open market.

Another pathway is via Australian Disability Enterprises (ADEs), which provide employment opportunities for young people in a supported environment. ADEs can also link young people to training and experiences that help transition into the open market. However, disability employment stakeholders identified low wages, segregated work settings and mixed long-term employment outcomes as significant issues encountered in this setting.³²

A third and emerging pathway is via a social enterprise. Social enterprises have seen success as an alternative

²⁷ Meltzer, A., Robinson, S. & Fisher, K.R. 2019. 'Barriers to finding and maintaining open employment for people with intellectual disability in Australia.' Social Policy Administration. 2019;1–14. <https://doi.org/10.1111/spol.12523>.

²⁸ Disabled People's Organisations Australia (DPOA). 2018. Fact sheet: Employment of persons with disability. https://dpoa.org.au/factsheet-employment/#_edn3

²⁹ OECD. 2017. *Connecting people with jobs: Key issues for raising labour market participation in Australia*. Paris: OECD Publishing. <http://dx.doi.org/10.1787/978926426937-en>

³⁰ Meltzer, A., Bates, S. & Robinson, S. et al. 2016. *What do people with intellectual disability think about their jobs and the support they receive at work? A comparative study of three employment support models: Final report (SPRC Report 16/16)*. Sydney: Social Policy Research Centre, UNSW Australia. 31 *Anglicare Australia. 2020. Jobs availability snapshot 2020*. Canberra: Anglicare Australia.

³¹ Anglicare Australia. 2020. *Jobs availability snapshot 2020*. Canberra: Anglicare Australia.

³² Disability Employment Australia. 2018. *Discussion paper response: Ensuring a strong future for supported employment*.

Case study 6: Joe and Sandra

Joe (21) lives with his parents and his brother in a house in Melbourne's outer northern suburbs. Sandra is Joe's mother and full-time carer. She describes Joe as a warm person who's very sensitive, friendly and affectionate – the type of person who would come to comfort you if he saw you were upset. Joe was diagnosed with a chromosomal abnormality and has a significant learning disability.

Meaningful experiences

Joe has been at his school for around five years now, continuing through an NDIS program. But his confidence and abilities haven't progressed much. Sandra believes that his disabilities are worse and has a suspicion that he isn't being pushed enough to learn practical skills.

Joe had difficulties relating to the other kids at his special school and hasn't been able to make meaningful friendships. Sandra believes Joe is higher functioning than his peers, which is why he hasn't made friends over the years. Joe has tried to go out for social activities but he finds this difficult due to the different levels of support needs.

Sandra encourages Joe to keep going to the school twice a week, as it's something to keep him busy. But Joe doesn't enjoy it there and would prefer to get a job.

"He said to me, 'I don't want to go back in there. I want to find a job and work.' He's been there a long time... five years, and he's gotten nowhere."

form of employment, providing work for young people with intellectual disability in supported settings while offering greater pay and involvement with the community. But positions in these settings are limited and can sometimes limit career choice and trajectories.³³

Through our conversations with young people and their carers, we heard about real frustrations in seeking employment and pursuing this pathway; frustrations that were underpinned by a lack of options, especially options coming out of school. Carers also noted a lack of guidance and support to find work and limited employer understandings or support for a young person's behaviour support needs. Disability employment stakeholders also pointed to a shortage of suitable employment options and opportunities.

At the same time, we found that Disability Employment Service (DES) providers responsible for placing jobseekers with intellectual disability into jobs are struggling to place young people into sustainable roles. In 2018, 29.5 per cent of DES service users found employment and only 5.8 per cent found full time work.³⁴ Disability employment leaders we interviewed highlighted that funding models focused on outputs (i.e. longer-term employment outcomes) are not working effectively to support young people with more complex needs.

Placing young people with complex support needs requires real time and support to find suitable work. However, employment leaders noted that in some cases, people with intellectual disability are being pushed into ADEs before exhausting other options, raising concerns on the level of choice provided to young people. From our conversations with carers, we saw some distrust in employment services and many carers assumed responsibility for job searching themselves.

Future directions

Opportunities for employment

Open employment opportunities are typically better for the financial and social wellbeing of young people with intellectual disability. Yet the lack of available and supportive opportunities in the open market for young people means too many miss out on this pathway.

There is a need for more programs targeted at building the awareness and capacity of mainstream employers to support young people with intellectual disability. Establishing more programs that create opportunities for traineeships and work experience in open employment could help to increase options for young people.

This work should build on existing work and efforts already being delivered across the sector such as the work of the

³³ Meltzer, A., Bates, S., Robinson, S., et al. 2016.

³⁴ Australian Government. 2018. *Employment services outcomes report: January 2018 – December 2018*.



Anthony Romagnano, Not titled, 2020

Australian Network on Disability, which runs a variety of programs targeted at building the capacity of mainstream employers and creating opportunities for work experience.

There is also potential for social enterprises to play a more significant role in providing employment opportunities for young people with intellectual disability. With rising investment in social procurement initiatives, there is potential to leverage the growth in this area and deploy more placements for young jobseekers with intellectual disability.

We found that ADEs continue to provide an essential service for many jobseekers who face barriers to finding employment in the open market. But we found there are persistent challenges in these settings relating to equal pay, social inclusion barriers and ineffective training

limiting prospects. There is a need for ADEs to review their business models to improve wages and ensure incentives are in place to link young people to training and work experience that lead to open market employment.

Future of jobs

Through this study, we found that the open employment market for young people with intellectual disability is increasingly competitive. And there is limited information on what the future job market could look like for these young people.

With the long-term economic impact of Covid-19 unknown and automation disrupting the job market, young people with intellectual disability are at risk of being left behind. So there is a need to better understand

their future employment prospects to ensure efforts are focused on areas that will most effectively support young people into sustainable employment.

Better placements

We found there is a need to strengthen the ability of placement services to successfully match more young people with jobs in the open market. This means ensuring the economics of contracting arrangements with DES providers allow services to provide the supports needed to find or create appropriate job opportunities.

Community participation

Community participation for young people with intellectual disability covers a broad range of activities and endeavours. It can involve young people participating in activities in the community, having diversity of choice, developing friendships, and engaging in and across the broader community.

Community participation has historically been a core aim for the disability support system and many interpretations of what it means have developed over the years. Not surprisingly, 75 per cent of NDIS participants with intellectual disability have social and community activities as a goal in their plans, highlighting the importance of social inclusion.

For young people with intellectual disability, community participation comes via a combination of formal and informal channels. Many young people will attend day centres or participate in community-based programs³⁵ run by NDIS providers, but these experiences can be mixed. While some are able to access meaningful programs, others encounter protectionism and limited opportunities for skill building and inclusion. We found from our conversations with carers, disability service providers and peak bodies that good community supports are typically driven by staff who take person-centred approaches to designing and delivering programs.

Many carers mentioned that young people with intellectual disability were often grouped with other people perceived to have similar needs. While more economical for providers, carers highlighted how these practices could restrict a young person's ability to spend time with friends or with

other people who have different support needs. We also found that, in some cases, community services continue to provide traditional programs that emphasise group activities and service efficiency over individual outcomes.

Across our interviews with the sector, we found that pricing structures and risk-based funding approaches were key issues that underpinned (and undermined) the variability in experiences across services. For example, some services noted that 1:1 supports were no longer viable and restrictive pricing models were limiting their ability to deliver inclusive community-based activities.³⁶ They also indicated that a risk prevention approach to funding and service delivery was often adopted, which limited opportunities provided.

Future directions

Viable operating conditions

Services require operating conditions that enable them to innovate and develop community participation opportunities. Creating these conditions requires pricing structures and funding approaches commensurate with real costs. This means adopting pricing levels that cover the additional costs associated with supporting people with intellectual disability. It also means funding approaches that recognise the dignity of risk, so providers are not forced to sacrifice community participation supports to run a viable service.

Community-based supports

Through our study, carers and community advocates highlighted the large variation in the quality and efficacy of supports encouraging community participation for young people with intellectual disability. As a result, there is a recognised need for an increase in appropriate services. Young people should be involved in the design of programs and staff require a clear understanding of best practice approaches to maximising participation for young people.

³⁵ Gray, K.M., Piccinin, A., Keating, C.M. et al. 2014. 'Outcomes in young adulthood: Are we achieving community participation and inclusion?' *Journal of Intellectual Disability Research*, 58, 734–745. DOI:10.1111/jir.12069.

³⁶ NDS. 2018. The impact of NDIS prices on day services. <https://www.nds.org.au/news/the-impact-of-ndis-prices-on-day-services-1>

Priority actions

Foundations for inclusion

- Commonwealth and state governments to work with schools and disability service providers to build the capacity of mainstream schools to support greater adoption of inclusive practices for young people with intellectual disability. This should include the provision of adequate funding and resources for schools to adopt more accessible learning environments. It should also involve resolving boundary issues between education and NDIS providers so young people receive disability supports in school settings.
- Commonwealth and state governments and funders to work with peak bodies, educators and academic partners to build the evidence base and understandings of best practice inclusive education for young people with intellectual disability. This should include the development of clear definitions of inclusive education; consideration of the efficacy of inclusive practices delivered for young people with intellectual disability within school settings; and development of new data collection systems and processes to monitor the take-up and effect of inclusive practices.
- Commonwealth and state governments, Australian Council of Deans of Education and schools to work with current and future educators to ensure initial teacher education has a focus on inclusive education practices for young people with intellectual disability.

Post school transitions

- Commonwealth and state governments to work with schools, NDIS services and employment services to ensure young people with intellectual disability have better access to long-term transition planning and preparation supports. This should include a focus on making supports available well before young people transition out of school, with access to information on post school pathways.
- Commonwealth and state governments and funders to work with peak bodies and academic partners to build the evidence base and understandings of best practice transition planning and support for young people with intellectual disability. This should include consideration of the efficacy of current practices and development of new data collection systems and processes to monitor the take-up and effect of transition planning.

Finding and keeping a job

- Commonwealth Government, disability employment services and employers to build the capacity of mainstream employers to increase employment opportunities for young people with intellectual disability. This should include providing education and capacity building supports for mainstream employers to better understand how they can effectively attract and support young people into sustainable jobs.
- Commonwealth Government and funders to support the development of social enterprises that support young people with intellectual disability into employment. This should include assisting new businesses through social procurement initiatives.
- Commonwealth Government to work with ADE providers to review current ADE business and economic models to broaden employment and training opportunities as well as working conditions (e.g. wages) for young people with intellectual disability.
- Commonwealth Government to review incentive structures for DES providers to ensure current services prioritise placement of young people with intellectual disability. This should include a review of current funding models to ensure services are incentivised to support the provision of additional supports for placing these young people into stable work.

Community participation

- As part of any future reviews of NDIS pricing, Commonwealth Government should consider the pricing and funding of community-based services for people with intellectual disability to ensure services can viably provide appropriate and sustainable supports without sacrificing activities that promote greater community participation.
- Commonwealth Government and disability service providers to ensure community-based supports for young people with intellectual disability prioritise community participation by including young people in the design of programs. Actors should provide targeted support to staff that promotes best practice approaches to community inclusion for people with complex needs.



Theme 3: A secure future

Independent living can play a significant role in creating stable futures for young people. Being independent is valued by young people and a greater level of independence has been related to increased feelings of happiness and better quality of life.³⁷

Many young people with intellectual disability require supports for independent living. In 2019, support for daily living and independent living were NDIS funded services with the highest levels of committed support for people with intellectual disability.³⁸ This includes specialised support to find and access suitable accommodation alongside ongoing provision of in-home supports.

The NDIS has provided more opportunities than ever for young people to secure lifelong supports. In combination with stable housing, young people can now access various supports required for a life of independence. While changes to the housing and support sector have come with an influx of opportunity, the sector has also experienced challenges. For example, Specialist Disability Accommodation (SDA) funded under the NDIS is experiencing suitability and supply issues. Also, restrictive policies are limiting access to desirable living arrangements, particularly for people with intellectual disability.

As people with intellectual disability start to live longer and carers age, it is important that succession plans are put in place to ensure continuity of supports through carer and informal networks.

Securing housing

Securing stable housing can play a significant role in supporting independence for young people and through our conversations, carers stressed its importance. They highlighted the challenge of long wait times and competing for access to a limited pool of housing options with appropriate levels of support.

Since the introduction of the NDIS, housing options and availability for people with disability have been transformed, with more opportunities for disability housing providers to innovate and increase supply of suitable housing stock. For example, the introduction of 'Robust' housing builds designed to support people with intellectual

disability and/or behaviour support needs have set a new standard for safe and suitable housing. But there is a significant shortfall in the supply of appropriate housing for people with intellectual disability. A recent report authored by Social Ventures Australia and The Summer Foundation on the SDA housing market in Australia³⁹ welcomed the growth of 3000 new places that have been built since 2015 or are now in the pipeline. But it is estimated 7750 places are still needed to meet current demand.⁴⁰ And with limited investment into Robust SDA housing, there is a gap between supply and demand for suitable housing for young people with intellectual disability.⁴¹

Our interviews with disability housing providers noted that it is critical to have an inflow of suitable financing to increase the construction of Robust housing.



Samuele Fenech, *Blue House*, 2014

³⁷ Sandjojo, J., Gebhardt, W., Zedlitz, A. et al. 2018. 'Promoting independence of people with intellectual disabilities: A focus group study perspectives from people with intellectual disabilities – legal representatives and support staff.' *Journal of Policy and Practice in Intellectual Disabilities*. DOI: 10.1111/jppi.12265.

³⁸ National Disability Insurance Agency. 2019. *People with an intellectual disability in the NDIS*.

³⁹ Winkler, D. & Ferner, D. 2020. *Specialist disability accommodation: Supply in Australia*. Summer Foundation, Social Ventures Australia.

⁴⁰ *ibid.*

⁴¹ *ibid.*

But they noted that the expected returns on building Robust SDA are not competitive with returns on other dwellings, discouraging investment from developers.

We also found that disability housing providers will often place a premium on vacancy and maintenance risks for Robust SDA, given perceived challenges in finding compatible tenants and navigating the complexities of behaviour support needs. Some providers have sought specialist tenancy matching support to manage the risk, incurring additional costs not covered by current financial models.

Disability housing providers also highlighted the information gap on the demand for Robust housing. Robust builds have very specific and complex design characteristics and this can lead to higher development costs. In the absence of reliable demand data and design requirements, it is difficult for providers to develop the confidence needed to invest and build these types of housing.

Future directions

Competitive returns

There is a need to improve the economics of Robust SDA to incentivise greater investment in the supply of suitable housing for young people with intellectual disability.

Disability housing providers noted that most vacancy and tenancy risks can be significantly reduced by developers forming close working relationships with Supported Independent Living (SIL) providers. These relationships could provide the opportunity to coordinate and manage vacancy and maintenance risks, and inform best practice design. Specialised support from SIL providers could significantly improve the economics of Robust SDA for developers.

There is also an opportunity to review current pricing and insurance policies for Robust SDA to ensure they are commensurate with other builds and function more effectively to encourage a greater supply.

Market information and guidelines

Our interviews with disability housing providers highlight the impact that limited information on demand is having on the confidence of providers interested in growing housing supply. Providing more information on where people with intellectual disability are living can offer a level of assurance to providers about the economic viability of

Case study 7: Mitch and Fran

Mitch (24) lives with his parents and sister Fran in their family home. Fran became Mitch's primary carer six months ago, taking over from their ageing parents. Fran says Mitch feels most comfortable in familiar environments. He enjoys being around his family and in his spare time playing games on his iPad. Mitch has an intellectual disability and has complex cognitive, communication and physical support needs.

Thinking about the future

Mitch is most comfortable in a familiar environment with his family so Fran wants to keep him in family care for as long as possible. Mitch is happy at home for now but there may come a time when the family needs to look more seriously into shared housing as an option.

Fran hopes to maintain as much consistency in his therapy as possible so that Mitch continues his progression and ultimately gains more independence. If Mitch can become more independent, his family would feel more comfortable with the idea of moving into supported accommodation.

There are concerns for Mitch's quality of life if he was to live in shared housing with non-family carers. Fran thinks that housing for people with disabilities is similar to nursing homes – it's not a very positive picture.

"I suppose I'm also thinking it's like nursing homes. I know that's a different environment... but I've heard so many horror stories."

future investments. As the primary steward for the NDIS marketplace, the NDIA could release more demand data and offer guidance to providers. The community sector can also share local knowledge with SDA providers. One example is the Summer Foundation: Specialist Disability Accommodation Supply in Australia report.⁴² Two reports were published based on surveys of SDA providers across Australia to determine how many SDA places have been constructed or planned. This provided, for the first time, information on current demand and market gaps.

⁴² Winkler, D. & Ferner, D. 2020.

Choice over living arrangements

Living arrangements that align to young people's needs and preferences can have a significant impact on quality of life. Preferences can come in many forms, including shared or independent housing; access to support staff; and access to amenities and family. Conversely, placing young people in unsuitable housing can negatively impact health and wellbeing, and heighten the risk of conflict or harm.

Through our study we found that young people with intellectual disability are often limited in their ability to find suitable accommodation and living arrangements. We heard from many carers about the lack of choice and housing options. For instance, some carers found it difficult to obtain appropriate staffing arrangements.

Others found it challenging to locate housing with access to local amenities and support services. We also found that limitations on choice start with the NDIA planning process.



Samantha Ashdown, Not titled, 2020

The Commonwealth Government's Report into Supported Independent Living (2020) found practices that encourage young people to live in congregated settings⁴³ where NDIA planners would default to placements in shared support arrangements before exploring other options. This happened despite policies highlighting the need to prioritise greater choice and control.

Another challenge is the lack of involvement of young people and carers in the tenancy management process. While preferences are considered when matching a young person to a potential home, from our interviews with peak bodies and disability service providers we found that many providers will take a vacancy led approach. Young people are often offered the first available property as opposed to the most appropriate option.

Disability service providers also highlighted the influence of funding shortfalls on their capacity to support young people with intellectual disability via the provision of SIL services. While the housing stock may be available, young people cannot occupy a dwelling without access to the necessary supports. This limits choices and placement of young people in secure and appropriate housing.

Future directions

Prioritising preferences

Providing choice and control to young people means embedding practices that include young people and prioritises their preferences. There is a need for the Commonwealth Government, the NDIA and disability housing and service providers to prioritise investment and policies that support choice and control for young people and carers.

We also found that more support and information needs to be available for young people and carers to navigate vacancies and the tenancy matching process. This means creating more mechanisms for providers to share vacancy information with the broader housing sector and establishing registers available to young people and their families when navigating potential options. Initiatives such as Northcott Innovation's Nest and Summer Foundation's HousingHub represent interesting case studies in this area. Both initiatives provide young people and carers with access to central registers of housing options in their area. Another case study is the housing matching service delivered via Supporting Independent Living Cooperative. It represents a more community-based

⁴³ Commonwealth of Australia. 2020. *Report into supported independent living*. Joint Standing Committee on the National Disability Insurance Scheme. ISBN 978-1-76093-083-7.

model connecting young people and carers directly with support staff, developers and the NDIA to develop tailored housing solutions.

Access to supports

Without the right supports, young people with intellectual disability cannot live independently in a safe and dignified way. So providing adequate funding for SIL supports is critical, with current funding understood to fall short of the real costs borne by providers. The Commonwealth Government's Report into Support Independent Living found funding for SIL supports and payments for vacancies do not adequately cover the real costs of supporting young people with intellectual disability.⁴⁴ Reviews of pricing for NDIS services and current standards should consider the full costs of providing the required supports so that people with intellectual disability can access their preferred living arrangements.

Planning for the future

Through our study, we found that the NDIS and other service reforms have improved the outlook for life-long care. But informal networks are still a core element of supports provided to young people with intellectual disability. Primary carers often make up a large portion of a young person's informal support network, providing close friendship and creating dependency. Many carers may not have expected to outlive their children in the past, but improvements to services and care have led to increased life expectancies, meaning this is becoming a common reality.⁴⁵

Engaging in succession planning is important to ensuring continuity of support into the future. It also represents a growing need, with research suggesting most carers do not have adequate plans in place despite being aware of their importance.⁴⁶

Future planning is a complex and challenging process. It requires significant effort to understand a young person's financial and support needs, and involves coordinating government services, communities, families and friends. This requires provision of appropriate guidance and support, which is not currently available.⁴⁷

Future directions

We recognise the important role that primary carers play in the life of a young person with intellectual disability and the time-bound nature of the care they provide. Having a succession plan that ensures the continuity of informal and other critical support arrangements is essential for securing ongoing independence.

Succession planning

The role that primary carers play in a young person's life cannot be overstated. These relationships provide stable support, love and friendship. A succession plan that ensures the continuity of informal and other support arrangements is essential for securing ongoing independence. Through our study, we found that succession planning needs to commence early and include financial planning, accommodation, family roles and guardianship. Having a wide range of publicly available resources and guidance for carers on the process can ease the burden.

⁴⁴ Commonwealth of Australia. 2020. *Report into supported independent living*.

⁴⁵ Walker, R. & Hutchinson, C. 2019. 'Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability.' *Ageing and Society*, 39:7. Cambridge University Press. DOI:10.1017/S0144686X18000144.

⁴⁶ *ibid*.

⁴⁷ Carers Victoria. 2017. *NDIS costs: Carers Victoria submission to the Productivity Commission*.



Priority actions

Securing housing

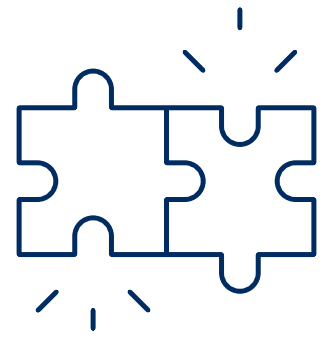
- Commonwealth Government to better align returns of Robust SDA with other builds to improve developer confidence and interest in Robust SDA.
- NDIA, alongside disability housing providers and peak bodies, to release more accurate information and data on the supply and demand of housing for people with intellectual disability.
- NDIA, alongside disability housing providers and peak bodies, to develop and share guidelines on good practice housing design and approaches to tenancy matching.

Choice over living arrangements

- NDIA to work with disability housing providers to better ensure young people with intellectual disability and carers are included in tenancy management processes and provided with genuine choice in living arrangements. This should include support for navigating vacancies and tenancy matching, and information services that help young people to navigate options.
- Commonwealth Government to review current pricing of SIL support to ensure standards cover real provider costs, and remove disincentives for supporting young people in their desired living arrangements.

Planning for the future

- NDIA to work with peak bodies and disability service providers to encourage greater engagement in succession planning for young people and carers. This could include producing and disseminating information and resources on approaches to succession planning alongside outreach support.



Theme 4: Robust disability services

Having services that provide high quality and appropriate supports for young people with intellectual disability is fundamental to improving health and wellbeing outcomes. Service provision for these young people can look very different to that provided for other groups. It requires integration with health and other mainstream services, highly specialised and well-trained support staff, and deep understandings of needs.

The NDIS has been one of the most important policy reforms in the new millennium, driving the creation of a national disability service system to deliver greater choice and access to services. While the NDIS is successful in improving quality of life for many, some cohorts still face issues in accessing the services they need. This includes people with complex needs such as young people with intellectual disability.

Acquiring supports

Underpinning the NDIS is an individualised planning system designed to assess the level of funding provided to a participant. Funding for supports is included in the plan based on conversations between a participant and the NDIA. This process is integral to driving a person-centred approach to acquiring supports and providing greater choice and control over services. Through our conversations with carers, we heard about significant improvements in the level of choice they had as a result of this approach. We also heard about challenges faced in acquiring appropriate supports. Many young people had delayed or no access to essential supports, largely due to the development of inappropriate plans.

For young people and carers, acquiring services is not always straightforward. The NDIS is a large and complex system with an unwieldy planning process, so young people can end up with support plans that do not meet their needs. Carers reported challenging experiences with confusing planning processes that led to erroneous or inconsistent decisions on supports. They also noted feeling misunderstood by planners who appeared to have a limited understanding of the unique needs of young people with intellectual disability.

Peak bodies, disability service providers and academic researchers interviewed in the study noted how the current

system lacks the flexibility or capability to support people with more complex needs. The 2019 Review of the NDIS Act 2013⁴⁸ highlighted challenges in the planning process for acquiring critical supports. It found the process was confusing and difficult to navigate. Key issues including miscommunication between planners and participants; disjointed planning processes; and unclear definitions of what constitutes reasonable and necessary supports (especially regarding complex support needs).

The review also found planners were not provided with the training they needed to construct plans for young people with intellectual disability.

We also heard about the challenges with navigating local services to acquire and utilise funding allocated in plans. The NDIS service system is large and complex, and with multiple and complex support needs, the best way to use funding in plans is not always clear. The NDIA has tried to assist by funding Local Area Coordinators (LACs) and high needs coordinators, who provide navigation and coordination assistance to acquire supports. The Review of the NDIS Act 2013⁴⁹ also found that LACs are often under resourced, trying to play dual planning and coordination roles. And support coordination is not always funded, leaving individuals and carers without enough assistance to realise funding in their plans.

Future directions

Adequate plans

There is an urgent need to make sure planning processes adequately support the needs of young people with intellectual disability. This means ensuring there are clear definitions on what constitutes reasonable and necessary supports in the context of complex needs. It also means providing planners and service providers with operational tools and training to identify support requirements for people with more complex needs, including young people with intellectual disability.

Utilising plans

There is a need and opportunity to increase the capacity of navigation and coordination supports to help young people with intellectual disability engage services and fully utilise their plans.

⁴⁸ Tune, D. 2019. *Review of the National Disability Insurance Scheme ACT 2013. Removing red tape and implementing the NDIS participant service guarantee.* Commonwealth of Australia.

⁴⁹ *ibid.*

Case study 8: Mark and Anna

Mark (7) lives with his mother Anna, father and four siblings. He currently goes to a special school. Anna is his primary carer and his older brother Nick also helps out. Anna describes Mark as happy, energetic, fearless and free spirited with a passion for planes. Mark has autism and complex communication needs.

Finding the right supports

Mark accesses speech therapy and occupational therapy through the one service and attends a private practice to access psychology services. He has an NDIS coordinator and two workers who take him out to provide respite for Anna. With three other school age children, there's a lot for Anna to keep track of. One of her biggest concerns is developing strong relationships with Mark's service providers. Two providers have recently changed, including his psychologist.

"It takes time to build that relationship, and then when you build it up it's gone again. It's hard. I'm starting again and it feels like we're going backwards."

Continuity is not only important for Mark's routine, but for his progress. The recent change in services means he's going without the support he needs as he waits for a vacancy to open.

"It's hard because he needs that service. He knows the days – Monday, Tuesday, Wednesday. He crosses them off in his diary. He wouldn't understand why a person is gone. Everything would be disrupted."

The psychologist has been an important source of support for Anna. This isn't the first time her access to the service has been disrupted. Changes to Mark's last NDIS plan about a year ago saw his funding cut in half. This restricted access to regular services and removed access for Anna. They lodged an appeal, which was rejected after a six-month wait.

"I didn't have enough OT lessons. I didn't have enough psych. I didn't have enough speech. I was drained physically and mentally because I didn't have any respite."

This last year has been an exhausting one for Anna, and one she considers a 'lost year' of development for Mark. The most recent plan is much better. Anna credits the improvement to taking the speech therapist and occupational therapist with her to the assessment.

Boosting the capacity of coordination functions offers would ensure young people can utilise their plans by acquiring services. This can be achieved by removing planning responsibilities from LACs so they can go back to their original navigation and coordination roles. Boosting funding for specialist support coordination could provide increased capacity for supporting young people and carers to make the most of their plans.

Supported decision making

There is a well-established connection between service choice (and autonomy) and improved health and wellbeing outcomes for people with disability.⁵⁰ Choice and control gives young people the opportunity to have their voice represented in decisions that impact

on their lives. From a system perspective, having informed and engaged choosers who can 'reward' good services drives greater efficiency in NDIS markets by incentivising high performing services⁵¹, driving innovation, getting more out of plans and improving equity of access. Underperforming services need to improve to attract clients or risk going out of business.

Young people with intellectual disability have barriers to decision making and self-advocacy that require tailored supports to enable them to make good choices. Through our study we found that the NDIS struggles to provide appropriate support for young people to exercise choice and control.⁵² Instead, it operates on the assumption that all people with disability know what is possible and available to them.

⁵⁰ Malbon, E., Carey, G. & Meltzer, A. 2019. 'Personalisation schemes in social care: Are they growing social and health inequalities?' *BMC Public Health* 19, 805. <https://doi.org/10.1186/s12889-019-7168-4>.

⁵¹ Institute for Government UK. 2020. Public service markets: A practical guide. <https://www.instituteforgovernment.org.uk/publication/market-stewardship-framework>

⁵² Carey, G., & Malbon, E. 2020. *Information sharing as market stewardship in the NDIS*. Sydney: UNSW CSI.

Case study 9: Leo and Sophia

Leo (19) lives with his brother and mother, Sophia, in the northern suburbs of Melbourne. Sophia describes Leo as spontaneous and very active. He has a lovely nature, always looking for opportunities to have fun, even when no-one else is. Leo has a significant intellectual disability and autism. He has complex communication and behavior support needs.

At 6'4" and 96 kg, he is much bigger than Sophia and her focus is on keeping him occupied.

Having options

When Leo turned 19, he and Sophia experienced a dramatic change in the services they received and their weekly routine. They were rejected by the program Leo and Sophia chose and Leo was taken out of another program because staff couldn't manage him.

"I was looking for somewhere with a nice setting, that was new, that had good care. But they wouldn't take him. They just fobbed us off and wouldn't give us a definite answer. So I had to try to find somewhere else."

Sophia is measured about the challenges of accommodating Leo's needs and recognises that he has needs that many services can find difficult to support.

"I just think most times, if they're going to knock us back, it's because they can't cope. And I do get that, because you've got to think about other people."

Leo can be impulsive and unaware of the rules and norms most people take for granted, which means he can easily put himself or others in harm's way. It's important for Sophia to feel confident that she can trust the service provider to be attuned to Leo's moods, needs and potential risks as they continually evolve. Sophia talks about making it up as she goes along and an ongoing process of trial and error. Keeping Leo doing activities he enjoys is the strategy that works best, but the options provided by behavioural management specialists are often inadequate.

"All we've really ever been offered in terms of behaviour management is schedules. We've had so many consultants and when they come in, they just get out the schedules. He can get through a schedule in two minutes. It's really repetitive, and then he'll crack it."

Leo's world has shrunk as he's aged. Activities Sophia and workers used to do with him have been progressively ruled out, including plane travel, visiting relatives, cooking classes, going to the pool and now even going on the train. Sophia wishes he could be with his peers. She says there's a lack of options for young adults like Leo, and she faces challenges in finding a service willing and able to accommodate him.

To address this issue, some carers explained that they self-financed strong advocates who understood the system and helped them to find high-quality supports. Others found the experience isolating, where the process of finding services was difficult to navigate. A recent study conducted by the Centre for Social Impact at UNSW found that only 15 per cent of providers believe there is enough advocacy for the people they support.⁵³

While LACs were introduced to deliver selected supports, the Review of the NDIS Act 2013 found this support is not readily provided due to limited resources and competing

on-the-ground priorities.⁵⁴ This is compounded by a strong push from the NDIA for self-management of plans, without providing the necessary supports to do so.⁵⁵ Decision making supports and responsibilities often fall on carers, disability service providers and informal advocates.

Feedback received from our study from carers, disability service providers, peak bodies and researchers suggested that young people achieved better outcomes when they had access to strong advocates who understood the nature of a young person's need and were able to navigate the NDIS.

⁵³ Carey, G., Weier, M., Malbon, E., et al. 2020. *How is the disability sector faring? A report from National Disability Services Annual Market Survey*. Sydney: CSI.

⁵⁴ Tune, D. 2019.

⁵⁵ Carey, G., Dickinson, H., Malbon, E. et al. 2020. 'Burdensome administration and its risks: Competing logics in policy implementation.' *Administration and Society*, 52:9. Sydney: UNSW CSI.

We also found from our conversations with carers and interviews with peak bodies and service providers that access to information on the NDIS decision making process is difficult for young people and carers to monitor and understand. Current approaches to information sharing often fail to reach participants while existing online registries and guides do not provide the right information for young people and carers to make informed choices.⁵⁶

Future directions

Community advocacy

There is a recognised need for more supports to be made available for young people with intellectual disability and carers to maximise choice and control. We found that community advocates (formal or informal) have helped many young people effectively navigate the system and access the support they need.⁵⁷ While available prior to the NDIS, funding for community advocacy was removed with the assumption that it would not be required under the new system.

Peak bodies, academic researchers and disability service providers suggested that more independent community advocacy services should be available to support young people and carers with navigating and understanding the system (e.g. self-advocating, making informed choices and resolving issues relating to services). This representation would help build the capacity of young people with intellectual disability to self-advocate for better outcomes and support market efficiency.⁵⁸

Trusted information

There is also a critical need to ensure young people and carers have access to information required to make informed choices. Strengthening access to locally relevant and trusted information can drive greater confidence in decision making.

Current approaches to information sharing channelled through online registries are not reaching the intended audience or achieving the desired outcomes.⁵⁹ Peak bodies and disability service providers highlighted that localised, independent approaches to information sharing are more effective methods and should be prioritised. Independent

information services such as IDEAS are starting to fill this gap by providing personalised information services to NDIS participants.⁶⁰

Flexibility to respond

Young people with intellectual disability often have fast changing circumstances and needs that require adaptability and flexibility in supports. Flexibility can also help providers to trial different combinations of supports and drive innovative solutions to achieve better outcomes.

Through our conversations with carers, we heard about the impact that low flexibility can have on the supports a young person receives. Some carers explained that they had self-funded services due to significant delays caused in changing plans.

Disability service providers noted that current planning processes and funding mechanisms are too rigid, limiting capacity to adjust supports in response to changing needs.⁶¹ As a result, young people can go through protracted review processes to make adjustments to plans, causing significant delays in service access. They also noted that the structure of current plans restricted their ability to mix and match support items, which could help to deliver a better and more efficient offering.

It was noted that the current pricing scheme does not consider local variations in costs and support configurations for participants or providers. Because support needs for young people with intellectual disability are complex, service costs can be hard to generalise, resulting in pricing levels mismatched to requirements. To address shortfalls, providers are often dipping into their own finances, impacting on their ability to deliver sustainable services and supports.

Future directions

Responsive plans

Responsiveness in support plans is needed to ensure supports can meet the fast changing needs of young people. A key enabler of responsiveness is having a degree of flexibility and control over the level of funding for supports

⁵⁶ Carey, G. & Malbon, E. 2020.

⁵⁷ Tune, D. 2019.

⁵⁸ *ibid.*

⁵⁹ Carey, G. & Malbon, E. 2020.

⁶⁰ *Ibid.*

⁶¹ Tune, D. 2019.



Samuele Fenech, *Not titled*, 2016

that gives providers the ability to respond. One way to achieve this is to instil greater flexibility in the planning process. This means having robust and timely processes that enable variations in funding of supports to quickly respond to changes in costs or support needs, opportunities for innovation and other operating conditions.⁶²

Local pricing

There is also an opportunity to shift more control of funding to the local level, where participants and providers have the best knowledge of required supports. The current centralised pricing models can be too far removed from local service delivery to make effective pricing decisions that reflect local conditions.

Pricing levels in some cases are difficult to generalise and require flexibility to adjust to different needs. Devolving some elements of funding decisions closer to service provision and user can ensure pricing levels are commensurate with the cost of delivering the required support⁶³ and allow providers to offer responsive services sustainability.

Diversity of options

An important feature of an effective market-based service system is availability of choice delivered via multiple services and providers.⁶⁴ Carers we spoke to stressed the importance of having options, highlighting that it normally takes trialling more than one service before finding a good match. We also heard that limited choice can result in a young person pursuing inappropriate support or no support at all.

Through our interviews with service leaders and research, the current and future capacity of the system to support people with complex needs, including young people with intellectual disability, was highlighted as a key issue. This observation is backed up by sector wide perspectives. A 2018 survey of disability services conducted by the Centre for Social Impact found that only 20 per cent of providers believed clients who they were unable to support could be adequately supported by another organisation. Another 40 per cent of services believed that young people's needs would only be partially met, or not met at all.⁶⁵

⁶² Carey, G., Malbon, E.R., Weier, M., et al. 2019. 'Making markets work for disability services: The question of price setting.' *Health and Social Care in the Community*. 00:1–8. <https://doi.org/10.1111/hsc.12780>

⁶³ *ibid.*

⁶⁴ *ibid.*

⁶⁵ Carey, G., Weier, M., Malbon, E., et al. 2018, *How is the disability sector faring? A report from National Disability Services' annual market survey*. ISBN: 987-0-7334- 3852-3.

A key issue impacting on service availability is the funding shortfall delivered through the NDIS. The Independent Pricing Review of the NDIS report by McKinsey & Company found pricing is hindering development and growth of services, particularly for providers supporting young people with intellectual disability.⁶⁶ The review found that funding in some cases is too low to attract new operators and services into the market.

Disability service providers we interviewed also noted that some providers will take on the additional cost burden themselves to deliver specialist supports. This includes extra costs incurred from activities such as delivery of specialist training, placement of specialised staff and provision of crisis support.⁶⁷ Due to this practice, these providers are unable to build the financial capacity to drive growth and innovation in supports.

Through our study we found that a lack of data transparency on demand in different areas was a key barrier to driving confidence to grow services. Services need to know where young people live and the operating conditions of their communities to ensure they can provide a service model that is financially and operationally viable.

Although the NDIA has made important strides in releasing more market data, current efforts are too basic or high level and do not provide the information necessary for service providers to make decisions on local delivery.

Provision of financially viable supports is sometimes not possible due to the absence of demand or other local conditions. These areas, known as 'thin markets', are prone to supply shortages, leading to young people missing out on services. Young people can have highly specialised support needs that are vulnerable to shortages.⁶⁸ In the absence of a clear strategy for funding 'providers of last resort' who address these gaps, young people with intellectual disability can miss out on critical supports.

Future directions

Sustainable services

Pricing must be set at levels that allow providers to operate and grow service options for young people with intellectual disability. Current pricing levels are not conducive to sustainable service provision, particularly pricing for providers working with people who require more complex supports. It is recognised that this is an ongoing

process and pricing levels will continue to be adjusted as the market matures. There is a continued need and opportunity for the pricing agency to ensure pricing levels are commensurate with the real cost of delivery to support a young person with intellectual disability.

Information stewardship

Increased availability of demand data is required to ensure providers can reach areas of unmet need for young people with intellectual disability. Specifically, there is a strong need for the NDIA and the disability service sector to release additional demand data and information to provide greater visibility and understandings about service gaps and opportunities. Without this, it will be difficult for service providers to effectively respond to needs in the community and reach young people with intellectual disability. An enhanced approach to information sharing that provides relevant and practical information on service demand and service gaps, operating at central and local levels, is required.

Thin markets

The ongoing issue of thin markets and limited provision requires rethinking and action. Thin markets vulnerable to supply shortages represent a growing concern among government and service providers. These markets are home to a significant number of young people with complex or high support needs. A strategy is required to ensure supports are available and that young people can access the services they need. Proactive commissioning of 'provider of last resort' services separate to the market system would represent one approach to fill gaps and create improved equity across the system.

A specialised workforce

The complexity of the health and support needs of young people with intellectual disability requires an experienced and qualified workforce and support environment. This includes having a sufficient and skilled workforce; staff who understand and have experiences supporting young people with complex needs; flexible access to additional resources; and regulatory systems that ensure services can provide minimum levels of support.

Through our conversations with young people and carers, the importance of having services and workers that

⁶⁶ McKinsey & Company. 2018. *Independent pricing review: National Disability Insurance Agency*.

⁶⁷ Fitzgerald, J. 2017. *Complex disability (with complex support needs): Engagement, reasonable and necessary supports, and cost drivers*. Scope Australia.

⁶⁸ Alliance20. 2019. Supporting people with complex and high needs. <https://alliance20.org.au/wp-content/uploads/2019/04/A20-Complex-And-High-Needs.docx.pdf>

understand the nature of a young person's disability and bring specialised capabilities was highlighted. Carers spoke of issues they had with finding services that understood or had experience supporting young people with intellectual disability.

Building capability is paramount to ensuring young people have access to a specialised workforce. Under the NDIS, demand for disability services is expected to grow significantly with more people having access to services than ever before. The Productivity Commission estimates that the NDIS workforce will need to increase by up to 90,000 full-time equivalent employees by 2025.⁶⁹

Growing a skilled and capable workforce will require a sizeable increase in specialist roles and training. Peak bodies and disability service providers we interviewed highlighted misconceptions and low levels of awareness about career pathways supporting young people with intellectual disability. .

We also found that working conditions can be poor for parts of the workforce. For example, a high portion of the workforce is on short-term or casual contracts, and pricing levels do not always allow providers to meet minimum award conditions or attract qualified staff.⁷⁰ Financial pressures also limit the training and support that can be provided to staff, presenting a missed opportunity to attract and upskill the workforce and deliver better support for young people. Better working conditions will be vital to attracting and retaining quality staff. This issue is only likely to increase given the forecast growth in demand for similar roles in the related health and caring sectors.⁷¹

Future directions

Specialised career pathways

Greater focus on career pathways is needed to increase the supply of a specialist workforce to meet growing demand. This includes creating tailored pathways starting from school through to post school education and running careers campaigns promoting jobs across the sector. Specific strategies need to address working conditions and establish the meaningful career pathways required to attract a high-quality workforce.

With the growth of the health and caring sectors, it is also important for the disability service sector to share capacity and encourage more integration that allows movement of professionals across industries. Consideration could be given to establishing integrated qualification models that recognise shared skills and capability.

Specialised training

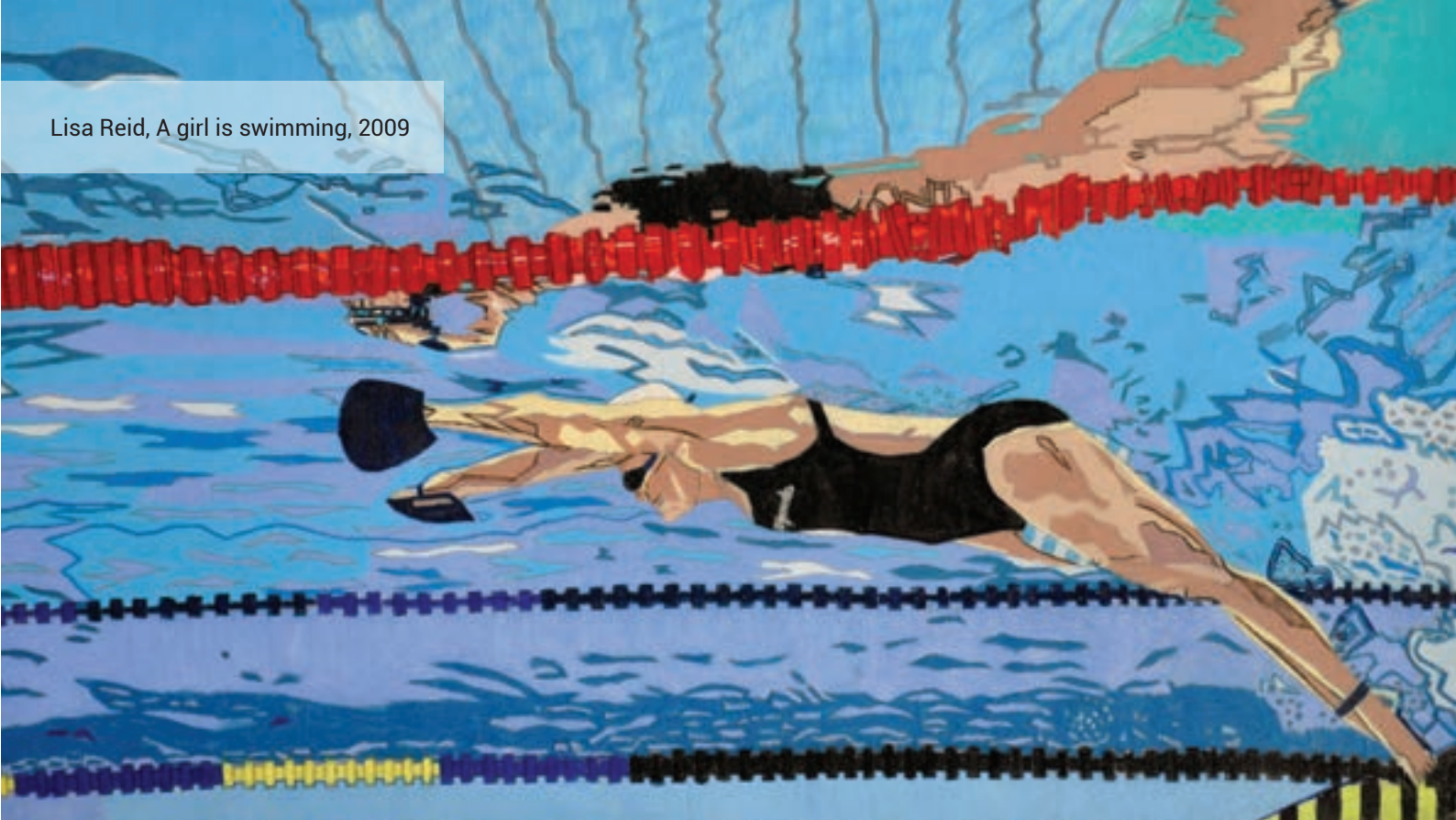
There is a need for more opportunities to upskill new and existing workers. Disability service providers and peak bodies interviewed highlighted the importance of having training programs in place to attract and retain an effective workforce. There is an opportunity for the NDIA to work closely with providers to ensure pricing levels are commensurate with what is required to allow providers to deliver appropriate training.

There is also an opportunity to build and grow staff skills by implementing a sector wide capability framework that explicitly includes the specialist support needs of people with intellectual disability. This could align to existing government efforts to upskill and build the sector workforce.

⁶⁹ Department of Social Services. 2019. *Growing the NDIS market and workforce: Supporting the market to deliver innovative, people-centred services so that participants can achieve their goals*. Commonwealth of Australia.

⁷⁰ VCOSS. 2018. *Supporting Australia's future community services workforce*. VCOSS submission to the Senate Select Committee on the Future of Work and Workers.

⁷¹ Department of Health. 2018. *A matter of care: Australia's Aged Care Workforce Strategy – report of the Aged Care Workforce Strategy Taskforce*.



Priority actions

Supported decision making

- Commonwealth Government to boost funding for independent advocacy and supported decision making services to help young people with intellectual disability and carers navigate the system, exercise choice and control, and have their voices heard.
- NDIA to work with peak bodies and disability service providers to increase the availability of service information for young people and carers. This should include a strong focus on local service provision.

Acquiring supports

- NDIA to commission an independent review of current planning processes, policies and procedures to ensure the provision of support plans for young people with intellectual disability is adequate. This review should consider understandings about 'reasonable and necessary' services in relation to people with complex needs; skills and capacity of planning staff working on complex needs; and overall user experiences.
- NDIA to review availability of LACs and specialist support coordinators to assist young people and carers to navigate the system. This review should consider the capacity of support coordination and navigation supports for young people provided via LACs, and provision of specialist support coordination.

Flexibility to respond

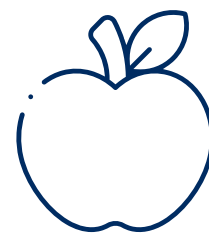
- Commonwealth Government to review funding policies and consider opportunities to establish more flexibility in the allocation and reallocation of supports in participants' plans to respond to changing needs.
- Commonwealth Government to consider opportunities to include additional input from local communities and services in pricing NDIS supports to ensure supports respond appropriately to local conditions and unique needs of young people with intellectual disability.

Diversity of options

- NDIA and Commonwealth Government, alongside peak bodies and disability service providers, to provide more locally relevant information on supply and demand of services for young people with intellectual disability.
- NDIA and Commonwealth Government to review current approaches and models to delivering services in thin markets to ensure young people with intellectual disability can access the support they need.

A specialised workforce

- Commonwealth Government to work with the NDIS National Quality and Safeguarding Commission to design a set of new initiatives targeted at growing the specialised workforce required to meet the needs of young people with intellectual disability. This should include consideration of career pathways, provision of on-the-job support and improving working conditions.



Theme 5: Healthy living

The physical and mental health of young people with intellectual disability is a critical indicator of current and future wellbeing. Given this cohort experiences a range of comorbidities, the complexity of need and required support is an ongoing consideration for young people, carers and service providers.

Through our conversations and work, we found that young people can fall through the gaps in the health system, encountering inequities and barriers to accessing critical services. We came across a range of issues including the level of preparedness and capacity of the health system to support young people with more complex needs, especially when it involves mental health problems. We also found there are opportunities for improved outcomes to be delivered through a more integrated care model, one that involves health and disability services working closely together.

Prepared health and mental health services

Young people with intellectual disability often have more complex health needs compared to their peers and require access to a broad range of health services and supports. It is critical that they have access to have health services and professionals who understand how to support and care for their needs.

Through our conversations with young people and carers, and interviews with health leaders, we found a range of issues impacting on outcomes including skill and capability gaps across professions. We heard from carers about the challenges in finding appropriately experienced health professionals. They noted instances where check-ups were avoided, as they were too difficult to manage when hospitals and clinics were unable to understand and support the complexity of need.

Overall, Australians with intellectual disability experience stark health inequalities compared to the general population. For instance, they experience twice the rate of avoidable death, lower rates of preventative healthcare and twice the rate of hospital admissions.⁷² Health professionals face challenges communicating with people

with intellectual disability, distinguishing health problems from disability and diagnosing complex health conditions. Most health professionals receive little or no training in intellectual disability healthcare.⁷³

In the area of mental health, the issue is particularly pronounced. It is estimated that 57 per cent of all people with intellectual disability have a mental illness⁷⁴ and are more likely to experience mental health problems during their transition to adulthood than the broader population.⁷⁵ Yet when young people seek mental health support, they often face challenges in accessing quality and appropriate services. We found from our interviews with health leaders that some services do not have the skills or capacity to deliver specialised care; care that recognises and caters for specific needs.

Disability service providers and health leaders noted that, as a minority group, young people with intellectual disability are often overlooked across mainstream policy areas. Despite experiencing some of the largest health inequalities in Australia, health policies and initiatives often lack explicit recognition or consideration of people with intellectual disability.

Future directions

Specialised health workforce

Through our study, we found a pressing need to upskill health and mental health professionals across the primary health network in supporting and caring for young people with intellectual disability to ensure greater equity in access to services. This will require the development of a broad set of strategies, including integrating relevant content into health qualifications and curriculum; training programs specifically aimed at improving capacity of health professionals in intellectual disability healthcare; implementing consistent competency requirements for practising professionals; and developing evidence-based tools to support diagnosis and delivery of health and mental healthcare.

Health services need to be made more accessible to young people with intellectual disability. This should include a focus on in-home visits and other adjustments to care settings that accommodate their needs.

⁷² Simpson, J. 2019. *The health of people with intellectual disability: Budget and federal election 2019 commitments sought from Australian political parties*. Council for Intellectual Disability.

⁷³ *ibid.*

⁷⁴ Trollor, J. & Small, J. 2019. *Health inequality and people with intellectual disability – research summary*. Faculty of Medicine, Department of Developmental Disability Neuropsychiatry 3DN. Sydney: UNSW.

⁷⁵ Dew, A., Dowse, L., Athanassiou, U., et al. 2018. *Making mental health policy inclusive of people with intellectual disability*. Faculty of Medicine, Department of Developmental Disability Neuropsychiatry 3DN. Sydney: UNSW.



Anne Lynch, *Not titled*, 2019

Integrating services

Young people with intellectual disability often have multiple and complex support needs that require interactions from a combination of NDIS, health and mainstream services. There is a critical need for integration in the planning and implementation of supports between systems.

Through our study, we found that the system does not always support the cross-sector and interdisciplinary interactions needed to provide holistic supports. A key issue is the absence of integrated planning and case management roles responsible for coordinating disability and mainstream supports. Unclear funding boundaries between health services and the NDIS were also identified as a pressing challenge, as they sometimes lead to unwanted removal of supports.

Traditionally block funded by state governments, funding for case management roles that help coordinate supports across different service systems have disappeared under the NDIS based on the view that this model can be disempowering and work against choice and control. But for people with intellectual disability, these functions can play a critical role in ensuring care plans and supports are integrated, accessible and managed from a single point of contact. In a health setting for example, a key worker

who knows a person's health history, understands their behaviour support needs, and can monitor any treatment and their health on a consistent basis, is critical to enabling health staff to treat health conditions.

The introduction of the NDIS Complex Support Needs Pathway is a welcome step. Strengthening this support can ensure young people are able to access integrated planning and coordination supports during the implementation of their plans.⁷⁶ But disability service providers and health leaders explained that disability and mainstream services have still been unable to adequately address the current gaps in provision.

Through our conversations with disability service providers and health leaders, we also found that instances of unclear service boundaries have led to the removal of services. This is an issue in the interface between health and disability systems where, for people with intellectual disability, the two services are highly interconnected. For example, when young people require hospitalisation a support worker would typically accompany the person into a hospital to assist them to communicate with health practitioners. Under the NDIS, it is unclear where funding for this the support is available once the worker enters the hospital.⁷⁷

⁷⁶ National Disability Insurance Agency. 2018. Improved NDIS planning for people with complex support needs. <https://www.ndis.gov.au/news/1002-improved-ndis-planning-people-complex-support-needs>

Case study 10: Dave and Sandra

Dave (28) was diagnosed with a rare chromosomal condition and an intellectual disability that was identified when he was a baby. He has complex communication needs and requires support to make decisions. Dave can understand his mother, Sandra, when she speaks to him in English or Lebanese. Sandra is Dave's full-time carer.

Receiving a diagnosis

Sandra's experience with Dave's diagnosis has left her with a deep mistrust of the health system. When Dave was a baby, Sandra knew there was something not quite right – he rarely smiled or cried and had difficulty feeding. Every fortnight, Sandra took him to the doctor to get him checked, but her concerns were often dismissed.

Sandra became increasingly distressed about Dave's condition, especially when he developed a spot in his eye. Again, Sandra sought support to have Dave checked. When he finally was, his eye had gotten worse.

"They said... the good news is, it's not cancer, but the bad news is he's lost sight in the eye."

Sandra was coming to terms with the fact that Dave would be blind in one eye when she received the call. Dave did have cancer and his eye would need to be removed immediately. Unfortunately, it took Dave losing his eye to also run the tests that would determine his current diagnosis. Sandra was told Dave would never walk or talk.

A year after the diagnosis, they were able to get a physiotherapist to come every week, which helped Dave achieve small improvements. Despite doctors saying he would never walk, Dave managed to start walking at age eight.

Future directions

Integrated supports

The provision of integrated planning and case management supports can improve coordination between disability and mainstream services. Operating at the local level, dedicated case managers are well positioned to play a vital role in ensuring consistent and accurate information is available between different services. This would assist with integrated care plans, facilitate open lines of communication and enable the delivery of more holistic supports.

Integration intermediaries within sectors can also play an important role in improving outcomes for people with intellectual disability. Functions such as the Intellectual Disability Health Team in Northern Sydney Local Health District, which provides young people with access to additional specialised coordination to navigate health services and care, represent promising bright spots within the current system.

Explicit funding boundaries

There is also a need to clarify funding for current responsibilities to ensure interpretations of responsibilities are consistently applied. Specifically, the Commonwealth Government and state governments need to clarify funding responsibilities and provide staff with sufficient guidance to ensure young people do not fall through the gaps and miss out on essential supports.

Right: Artist, title, year



Priority actions

Prepared health and mental health services

- Commonwealth Government and state governments to work with health services to strengthen the preparedness and capacity of health services and professionals to support young people with intellectual disability. This should include a focus on specialised education, training and guidance.

Integrating services

- Commonwealth Government and state governments to work with the NDIA and health services to strengthen integrated planning and case management functions. This will support greater integration and coordination between the NDIS and other mainstream services for young people with intellectual disability.
- Commonwealth Government to work with state governments to clarify funding boundaries and responsibilities regarding the provision of health services and support to young people with complex health needs.



Theme 6: Community attitudes

Positive attitudes towards people with intellectual disability can have a real impact on quality of life and wellbeing. A social model of disability is widely recognised as central to ensuring the rights and freedoms of people with disability. A core tenet of this model is the need to address societal and attitudinal barriers to allow people with disability to thrive in community.⁷⁸

Through our conversations with carers, we heard about the negative impacts of protectionist attitudes and negative perceptions on young people's confidence and willingness to participate in the community.

Societal attitudes were identified as a root cause of many inequities experienced by young people with intellectual disability across all stakeholders we interviewed.

In recognition of the link between community attitudes and improved outcomes for people with disability, The National Disability Strategy 2010-2020 committed to promoting awareness and removing societal barriers preventing people with disability from participating as equal citizens.⁷⁹ Through this period, our community has seen important advances in this area. For instance, a review of the National Disability Strategy conducted by the UNSW Social Policy Research Centre found overall improvements in community attitudes and awareness, increased media attention associated with the NDIS and a general paradigm shift towards human rights language and approaches.⁸⁰

Yet while perceptions are changing, people with intellectual disability still experience some of the highest rates of discrimination and stigmatisation in Australia.

A recent survey conducted by the Endeavour Foundation showed that almost 25 per cent of people would feel discomfort sitting next to a person with severe intellectual disability on a bus or train.⁸¹ These attitudes and experiences of stigma and discrimination seem to play out both the community and the service system.⁸²

Negative community attitudes and stigmatisation can also contribute to experiences of abuse. People with intellectual disability are more likely to experience violence, emotional abuse and sexual harassment.⁸³ Negative attitudes that people, communities, organisations and government have towards young people with intellectual disability can inform laws, policies and practices with potentially harmful consequences.⁸⁴ The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is shining a light on the inequalities and mistreatment experienced by people with disability in Australia.

Future directions

Changing mindsets

To ensure young people have access to pathways to a meaningful life in the community, there is a need to change community mindsets and shift the paradigm to one of inclusion and acceptance. There is an opportunity to combat negative and protectionist attitudes by investing in stronger community education and engagement initiatives, designing campaigns to target discrimination, violence and neglect, and promoting more positive narratives. While initiatives of this kind will have a broad focus, it is imperative that young people with intellectual disability are fairly represented with a focus on acceptance as opposed to sensationalising their experiences.

There is also a need for more research on the prevalence, impact and drivers of stigma and discrimination for people with intellectual disability in the community. This can help to concentrate efforts on developing a set of evidence-based actions to reduce discrimination and improve community attitudes.

⁷⁸ Australian Federation of Disability Organisations (AFDO). 2020. Social model of disability. <https://www.afdo.org.au/social-model-of-disability/>

⁷⁹ Commonwealth of Australia. 2011. *2010–2020 National Disability Strategy: An initiative of the Council of Australian Governments*.

⁸⁰ Davy, L., Fisher, K.R., Wehbe, A., et al. 2018. *Review of implementation of the National Disability Strategy 2010–2020: Final report*. (SPRC Report [4:19]. Sydney: Social Policy Research Centre, UNSW.

⁸¹ Michael, L. 2020. 'Aussies 'uncomfortable' with students with intellectual disability in their child's school.' Probono Australia, Feb 2020. <https://probonoaustralia.com.au/news/2020/02/aussie-parents-uncomfortable-with-students-with-intellectual-disability-in-their-childs-school/>

⁸² Pelleboer-Gunnink, H., Wietske van Oorsouw, M.W.J., van Weeghel, J. et al. 2019. 'Stigma research in the field of intellectual disabilities: A scoping review on the perspective of care providers.' *International Journal of Developmental Disabilities*, DOI: 10.1080/20473869.2019.1616990.

⁸³ Centre of Research Excellence in Disability and Health. 2020. Prevalence of violence and abuse of people with disability in Australia. <https://credh.org.au/nature-and-extent-of-violence/>

⁸⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. *Issues paper: Rights and attitudes*. Commonwealth Government.

Case study 11: Emma and Brad

Emma (28) has been living independently for the last six years. Brad, her father, describes her as a generally happy, bubbly person who enjoys travelling. Emma likes to share experiences with other people and is always looking for opportunities to be in other people's company. Emma has a significant intellectual disability and autism. She likes routine and has complex communication needs.

Understanding disability

Emma's complex needs haven't always been well understood by her community. Emma has been living out of home for six years now and while the experience has mostly been positive, there have been a few challenges in trying to navigate a world that doesn't understand her disability.

Brad recalls one specific incident where a misunderstanding of her behaviour support needs led to an avoidable escalation of a routine situation. In this situation, Emma was at her first supported accommodation when she became disorderly towards staff and started pushing things over in the house. During this time, the home was also understaffed.

"All the day staff had gone at this stage and they were down to two staff... the perfect storm of all these things going wrong. The staff there didn't know what to do, so they called the police."

When three police officers turned up, one of the officers tried to diffuse the situation and started shouting at her to try and get her to stop and calm down. This led to a bad reaction from Emma that provoked physical intervention from the officers. Brad thought that seemed like a pretty natural reaction from Emma given her sensitivity to the actions from the officer.

"And of course, the police did what they're trained to do when an officer's in trouble. They restrained and placed her in handcuffs."

Eventually an ambulance was called and took her to a hospital psychiatric ward, where she was later picked up by a family member.

Priority actions

- Commonwealth Government to work with disability sector advocates, carers and young people to design and launch targeted community education and engagement campaigns that promote positive attitudes towards people with intellectual disability.



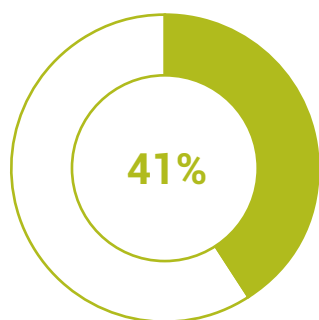
Patrick Francis, *Not titled*, 2015

Covid-19 reflections

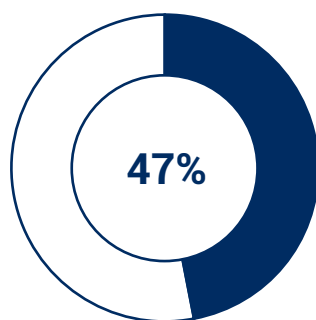
The Covid-19 pandemic has resulted in an unprecedented global health and economic crisis. It has transformed how we work, live and connect with others across the community.⁸⁵

Key reflections

Young people with intellectual disability are particularly vulnerable in the current crisis, even with Australia faring relatively well compared to other nations. This is due to the higher risk of illness for these young people given the prevalence of complex health conditions across the cohort; a strong reliance on formal and informal supports, which have and continue to face disruption; compounding challenges finding work; and enduring barriers to social inclusion, which are heightened with restrictions on social activities.⁸⁶



People with disability who reported receiving less NDIS support during the Covid-19 crisis.



People with disability who reported receiving less non-NDIS support during the Covid-19 crisis.

A recent survey by People with Disability Australia found that, during the Covid-19 crisis, 41 per cent of people with disability reported receiving less NDIS support and a further 47 per cent reported receiving less non-NDIS support.⁸⁷

Emerging issues and challenges faced by young people with intellectual disability due to the Covid-19 pandemic identified through interviews with sector leaders and a scan of publicly available information include the following:

Existing issues with service access and inclusion are exacerbated:

Even before the pandemic, young people with intellectual disability experienced inequities in accessing critical

Young people with intellectual disability are particularly vulnerable in the current crisis, even with Australia faring relatively well compared to other nations.

health and mainstream services due to system barriers and lack of inclusion in policy initiatives. With access to services restricted, changed or varied across the current period, including for young people with intellectual disability, this issue has become more pronounced even with the increasing use of e-health and telehealth practices. The Disability Royal Commission heard there was no mention of people with disability in the government's first pandemic plan, with ongoing confusion on whether disability supports are included in the government's definition of 'essential'.⁸⁸

Young people with intellectual disability are more vulnerable to abuse, violence and neglect, potentially escalated in times of crisis:

People with intellectual disability are at a far greater risk of violence, abuse, exploitation and neglect than their peers. There has been concern that lockdowns and restrictions may result in increased risk of harm. This is in part due to the expectation of reduced oversight and quality control mechanisms that increase risk of violence, abuse and neglect in congregated and closed residential settings.

Increased financial pressures for disability services during the crisis could threaten the sustainability and future viability of much needed supports:

Having resilient services that can thrive during and after a crisis is integral to ensuring young people continue to receive services critical to sustaining a quality of life. However, charities are more vulnerable in times of crisis. A recent SVA and CSI study found that a 20 per cent fall in revenue would place 17 per cent of charities at risk of closing their doors within six months.⁸⁹ With the medium-term and long-term economic situation not known, the financial situation of many charities is at risk without continued government support and intervention. In the case of disability services, there is concern about the



Cathy Staughton, *Not titled*, 2020

impact of a long-term economic downturn on the capacity of the sector to survive without serious adjustments. Short-term, current and emerging financial constraints may limit providers' ability to invest in new technology and infrastructure to maintain service delivery.

Closing the digital gap is critical to ensuring young people with intellectual disability are included in the emerging digital transformation:

Since the start of the Covid-19 pandemic, Australia has seen a rapid digital transformation with a significant uptake in technology to manage work and personal affairs. Many are anticipating the digitisation of society to be a critical part of how people interact and operate in the post-COVID world. Increased uptake of telehealth, rapidly improved technology infrastructure and increasing uptake of digital services will change the way services are delivered. While the potential impact is significant, this transformation requires careful consideration of digital access and the technological literacy of different groups to avoid further instances of exclusion.

Long-term economic impact of Covid-19 projected to impact on job opportunities for young people with intellectual disability:

The Covid-19 pandemic has brought with it the worst economic recession in Australia since the Great Depression.⁹⁰ Historically, unemployment has risen quickly in recessions but taken longer to come down. For example, it took 7.6 years to recover from the last recession.⁹¹ One study found that people with disability are more likely to be in vulnerable households hit hardest by the economic impact of Covid-19.⁹²

Young people with intellectual disability faced barriers to finding work in open employment well before the pandemic. There are concerns as to whether these barriers will become more prominent given the unequal impact the pandemic has had on industries where many young people with intellectual disability seek work.⁹³ Plans for economic recovery need to include those put at most risk by the pandemic, including these young people, to ensure they are not left behind on the road back.

⁸⁵ For the purposes of this discussion, we have used our best efforts to capture what we heard from system actors as well as found in the emerging research and commentary to highlight different experiences of young people during the crisis. Many outcomes and experiences are not yet known and will only emerge over time.

⁸⁶ Australian Federation of Disability Organisations (ADFO). 2020. An open letter to the National Cabinet: Immediate actions required for Australians with disability in response to coronavirus (COVID19).

⁸⁷ People with Disability Australia. 2020. *People with disability and Covid-19*.

⁸⁸ Eastman, K. Opening Address Senior Counsel Assisting, Kate Eastman SC. Hearing on the experiences of people with disability during the ongoing Covid-19 pandemic. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

⁸⁹ Social Ventures Australia & Centre for Social Impact. 2020. *Will Australian charities be Covid-19 casualties or partners in recovery? A financial health check*. Social Ventures Australia.

⁹⁰ Daley, J., Wood, D., Coates, B. et al. 2020. *The recovery book: What Australian governments should do now*. Grattan Institute.

⁹¹ *ibid*.

⁹² Melbourne Institute of Applied Economic and Social Research. 2020. *Who's hardest hit by the economic effects of the Covid-19 pandemic?* University of Melbourne.

⁹³ *ibid*.

Conclusion

This report provides a snapshot of the lives of young people with intellectual disability. We used our best efforts to elevate the unique experiences and views of young people and their carers.

We also included various perspectives on priority actions to drive better outcomes and deliver meaningful improvements and change to their lives. These actions build on the collective knowledge, learnings and existing efforts from across the sector.

We acknowledge that there is more work to be done. Efforts need to be directed towards elevating the voice of young people directly. There is also a need to complete additional research and analysis in areas where the prevalence and scale of issues is not understood. And there is a need to maintain a focus on the impact of Covid-19 on the lives and experiences of young people.

We hope that, from this work, others can further raise the voices of young people with intellectual disability. Please join us to elevate the experiences of young people with disability so that we can have a truly inclusive service system in Australia.


ARTS PROJECT AUSTRALIA

Arts Project Australia is an internationally renowned social enterprise based in Melbourne that supports artists with intellectual disabilities through its studio and gallery, promoting artists and advocating for their inclusion in contemporary art practice.





Samantha Ashdown, Not titled, 2020



Cover image:
Anthony Romagnano,
Grace Jones, 2018

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