



Reaching Potential

Experiences of young people with
significant intellectual disability

Summary Report

SVA Consulting

Limb
Family
Foundation 

Anthony Romagnano,
Spencer and Collins Street, 2019



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All images in the report have been supplied by Arts Project Australia.

Introduction

Young people with intellectual disability need to be included and engaged in policy, service design and the broader community, ensuring there is explicit recognition of their unique circumstances and support needs

Young people with intellectual disability are at heightened risk of experiencing disadvantage, exclusion and inequality.

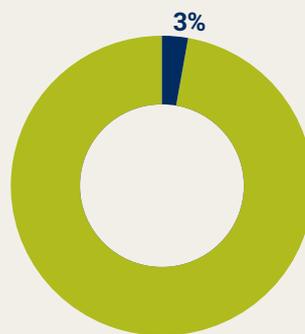
All young people should have the opportunity to pursue lives of their choosing – lives that are rich with opportunities to learn, work, connect with others and engage in and with their community. Yet young people with intellectual disability face barriers to accessing the support, services and experiences they deserve, driving inequities in health, education, social and employment outcomes.

While recent reforms and investments such as the National Disability Insurance Scheme (NDIS) have created opportunities for young people with intellectual disability, there is still significant room for improvement. More work needs to be done to ensure young people are provided with equal opportunities, particularly as society continues to navigate the impact of the Covid-19 pandemic.

The adjacent image source is: ABS 2012 *Intellectual Disability in Australia*; CID 2019. The health of people with intellectual disability 2019, ABS.2018. *Disability, Ageing and Carers: Summary of Findings*: Centre of Research Excellence in Disability and Health. 2020. *Prevalence of violence and abuse of people with disability in Australia*.

The focus of this report is to better understand the experiences of young people with intellectual disability

This report explores the experiences of young people with intellectual disability, focusing on those with more significant support needs. In undertaking the research, we wanted to learn about young people's hopes and aspirations for the future. We also wanted to learn about their experiences of education, work and community.



3 Percent
of the Australian population have an intellectual disability

This includes
300,000
Young People
with an intellectual disability



Compared to other Australians, people with intellectual disability...



Experience **2.5 times** the number of health problems



Are **2.5 times** less likely to finish year 12



and are over
2 times more likely
to die of preventable causes



and are
2 times less likely
to be in employment



experience **some of the highest rates** of discrimination and stigmatisation

Methodology

Anchored in understanding the experiences of young people with intellectual disability, we adopted tailored methods to build an understanding of opportunities across the system of supports.

1. Conversations with young people and their carers

We talked to 11 young people and their carers - each at very different stages of their lives and with their own unique stories. These stories have been told and shared by carers with select contribution from young people themselves. We appreciate this is a limitation of our work, and ongoing work is required to better capture the voices of young people directly.

Childhood (0-15 Years)

Mark (7) and Anna (mother)
Shaun (10) and Maddy (mother)

Transition to adulthood (16-24 years)

Leo (19) and Sophia (mother)
Joe (21) and Sandra (mother)
Mitch (24) and Fran (sister)
Katherine (24) and Lisa (mother)

Adulthood (25 – 35 years)

Nathan (25) and Jodie (mother)
Dave (28) and Sandra (mother)
Pete (28) and Steph (sister)
Emma (28) and Brad (father)
Connor (36) and David (carer)

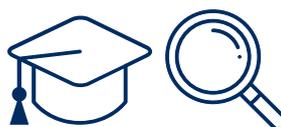
2. Understanding sector perspectives

Building on our conversations, we identified six themes that had a particular impact on young people's experiences. Across these themes, we completed a targeted review of available research, reports and key government policies and programs to identify opportunities to support young people achieve better outcomes. In parallel, we interviewed service and sector leaders to understand their perspectives on the most pressing challenges and opportunities.



10 x Leading Service Providers

across disability community, housing and employment supports



7 x Leaders in academia and research

across health, housing, education and disability services



5 x Peak bodies and advocacy groups

representing young people with intellectual disability across Australia

3. Proposing future priorities

We synthesised what we heard through our conversations and research to draw linkages with the challenges faced by young people. Following this, we identified key themes and priority actions for the sector to work differently so that they can more effectively support young people with intellectual disability.

Profiles

We talked to 11 young people and their carers - each at very different stages of their lives and with their own unique stories

Childhood (0-15 years)

Mark (7) and Anna

Mark is a happy, energetic, fearless and free spirited child with a passion for planes. He currently attends a special school. Mark has autism and complex communication needs. Mark and Anna are looking for opportunities for Mark to socialise and make friends at school.

Shaun (10) and Mandy

Shaun is a bright and friendly child who loves swimming, playing ball sports and making pancakes. Shaun has a significant intellectual disability. He needs some support to communicate and is learning how to sign. Shaun and Maddy are working with therapists to continue building Shaun's communication skills.

Transition to adulthood (16 – 24 years)

Leo (19) and Sophia

Leo is spontaneous and a very active person who is always looking to have fun. Leo has a significant intellectual disability and autism, and has complex needs. Leo and Sophia are looking for a day service they trust and where Leo can be around his peers.

Joe (21) and Sandra

Joe is a warm person who's very sensitive, friendly and affectionate. Joe was diagnosed with a chromosomal abnormality and has a significant learning disability. Joe and Sandra are in the process of finding a job for Joe.

Mitch (24) and Fran

Mitch 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. Mitch and Fran are working on building Mitch's independence so he can live on his own.

Katherine (24) and Lisa

Katherine is an inquisitive person with a quirky sense of humour. She enjoys swimming, art and being in the outdoors. Katherine has a moderate intellectual disability, autism and generalised anxiety. Katherine and Lisa are trialling different types of medication to help Katherine with her anxiety.

Adulthood (25 – 35 years)

Nathan (25) and Jodie

Nathan spends a lot of his time with friends and can be very chatty. He is very social and resilient. Nathan has cerebral palsy and uses a wheelchair. Nathan and Jodie are building a share house together with two of Nathan's friends.

Dave (28) and Sandra

Dave is bilingual, and can understand both English and Lebanese. Dave has complex communication needs and requires support to make decisions. Dave and Sandra are trying to create a safe environment in Dave's day program.

Pete (28) and Steph

Pete is a trusting and cheeky person, and likes to play tricks on his young nieces. Pete has an intellectual disability and physical and communication support needs. Pete and Steph are working with services to build Pete's independence.

Emma (28) and Brad

Emma, a happy and bubbly person, has been living independently for 6 years. Emma has a significant intellectual disability and autism. She likes routine and has complex communication needs. Emma and Brad are working on building Emma's decision making skills.

Connor (36) and David

Connor has become well known for his art and photography in his community. Connor had a seizure after he was born and has a moderate intellectual disability. Connor is looking for stable work so he can move out on his own.



Samantha Ashdown, Not titled, 2020

Case Study 1: 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.

Context

Contrary to his capabilities, Nathan 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 has severe cerebral palsy and uses a wheelchair. He and Jodie live in a house in a northern Melbourne suburb.

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.

The mainstream school was good for Nathan from a social perspective, as there were few 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.

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

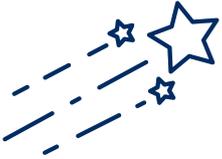
"They're actually starting to write up incident reports... but it's not the criminal offence they make it out to be. Because I'll ask him why and he'll give me a reason like ... 'I wanted to say hello' or 'That worker wasn't listening to me'."

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.

Insights into action

Across our study, six themes were identified as key influences on the experiences of young people with intellectual disability.



Theme 1 Rich and diverse aspirations

Insights

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 supported or engaged to envision a rich and diverse future. Barriers to communication and self-advocacy can cause tensions that can lead to their exclusion from decisions that matter to them, and for many young people, it isn't always clear what pathways are available. While there is recognition that goal-orientated services are critical in establishing a high quality of life, there is little agreement or clarity on what this looks like for supporters and young people alike.

Future directions

A focus and set of efforts is required to ensure young people are given real opportunities to meaningfully participate in decisions that matter to them. To do this, young people need to be provided with the information and supports required to appropriately engage with and contribute to these conversations. This includes providing a clear understanding of the potential pathways and prospects.



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

Insights

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 and post-school education. However, young people with intellectual disability face real challenges across these domains. Resourcing of additional supports can be hard to come by, and young people with intellectual disability are more likely to experience social exclusion. Importantly, we found young people are particularly vulnerable during transitions.

Future directions

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. These organisations need to be adequately resourced to meet the needs of young people with intellectual disability.



Samantha Ashdown, Not titled, 2020



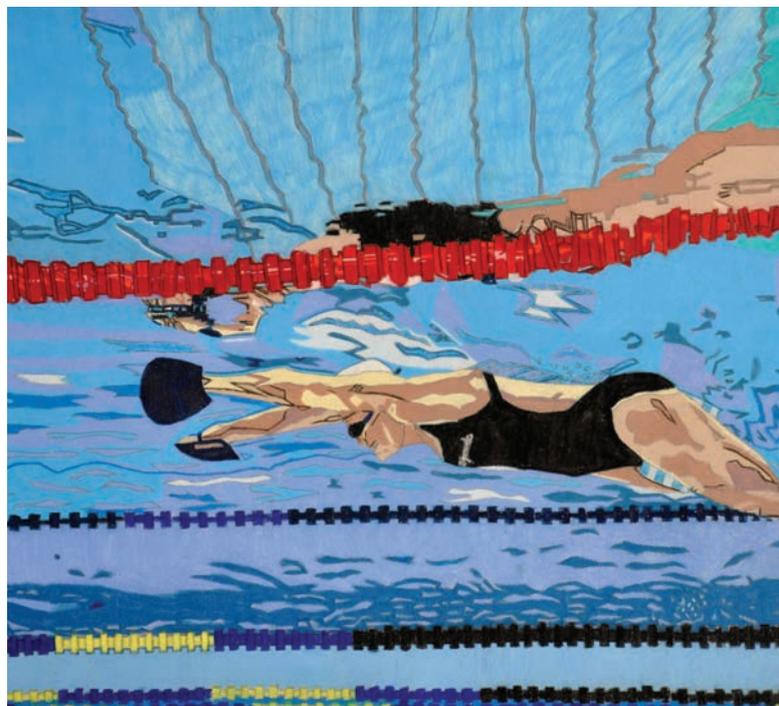
Theme 3 A secure future

Insights

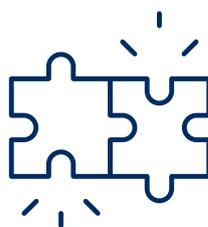
Secure and stable housing is a critical aspiration and goal for many young people and carers as it is a real marker of independence. Despite advances in disability accommodation, we found current market conditions aren't conducive to driving a greater supply of suitable housing and supports are not always available in people's preferred living arrangements. We also heard that succession planning is becoming critical as more people with intellectual disability start to live longer and carers age.

Future directions

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 preferred living arrangements. Also, assistance with succession planning can ensure continuity of support for young people with ageing carers.



Lisa Reid, A girl is swimming, 2009



Theme 4 A robust disability services system

Insights

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 also lack the flexibility required for the changing needs of these young people and there is a growing shortage of skilled staff. We found the NDIS struggles to provide appropriate supports for young people to make informed choices, instead operating on the assumption that all people with disability know what is possible and available to them.

Future directions

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 make informed decisions and exercise choice and control.



Matthew Gove, *Birdie and me*, 2019



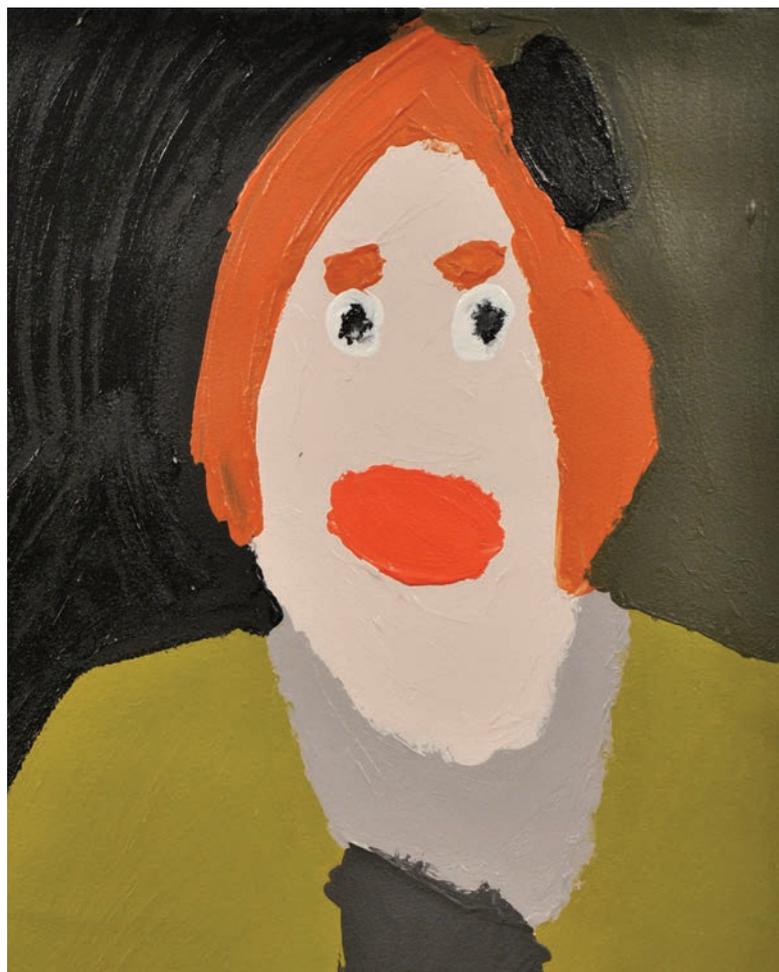
Theme 5 Healthy living

Insights

Having good physical and mental health is critical 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. However, 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 issues. There are also challenges to integrating care between health and disability services due to boundary issues and an absence of responsibility over integrated planning and support duties.

Future directions

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 and mental health services and professionals is necessary to support the complex health needs of young people with intellectual disability.



Patrick Francis, *Not titled*, 2015



Theme 6 Community attitudes

Insights

Above all, we found accepting disability in society is fundamental to improving outcomes for young people with intellectual disability. Negative community attitudes were frequently found to be a root cause of inequities and poor outcomes. We found a real opportunity in combatting negative and protectionist attitudes to promote more positive narratives and encourage acceptance of young people with intellectual disability in the community.

Future directions

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

Covid-19 reflections

While Australia has fared relatively well in managing the pandemic compared to other nations, it exposed the serious and on-going exclusion of people with disability in policy and service design.

Below are five reflections on the implications of Covid-19 on young people with intellectual disability, building on the findings in this report.

1. Existing issues with service access and inclusion were exacerbated during restrictions caused by a pandemic
2. Young people with intellectual disability were more vulnerable to abuse, violence and neglect – and the risks are potentially escalated in times of crisis
3. Increased financial pressures for disability services resulting from the health and economic crisis could threaten the sustainability and future viability of much needed supports
4. There is a growing need to address the digital gap faced by young people with intellectual disability to ensure they are an included participant in the future digital transformation
5. There is likely to be real and lasting impacts on job opportunities for young people with intellectual disability resulting from the economic crisis facing many employers across Australia

Conclusion

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.

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.

Anthony Romagnano
Not titled, 2020





Cover image:
Anthony Romagnano,
Grace Jones, 2018

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