

What finishing school is like for youth with intellectual disability

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Leaving school and figuring out what's next is challenging for young people. For those with disability, it is even harder. It is often a time



when supports are withdrawn as they leave the heavily structured school environment.

We asked young people with intellectual disability about their experiences of transitioning from school and starting <u>adult life</u>. <u>Our newly published research</u> suggests pre-transition planning for school leavers with disability is inconsistent or lacking. Most participants felt excluded from making decisions for life after school and needed support to access and navigate the National Disability Insurance Scheme (NDIS).

After school, most participants longed to find a paid job, friends, and a <u>life partner</u> but felt they were missing out on these typical adult milestones. They told us it was difficult to find service providers to help them reach their goals. Many felt isolated and in a perpetual state of transition.

The promise of 'choice and control'

Transition-from-school policies and guidelines exist in all states of Australia.

Shared <u>characteristics</u> between these guidelines include early planning, being person-centered, and ensuring collaboration between the family, school and services.

A decade ago, Australia changed from a social welfare model of disability support to a consumer-focused, market-based system. The NDIS promised to be the cornerstone of this, offering participants increased "choice and control" over new skills, jobs, greater independence, quality of life and improved social participation.

We wanted to understand the lived experiences of today's young Australians with intellectual disability in planning to leave school and



transition into adult life.

Through individual and group interviews, 27 young people with intellectual disability (15 female and 12 <u>male participants</u>, aged 19 to 33) told us their views and experiences of leaving school in New South Wales, Queensland and Victoria.

Their stories highlight how much more work should be done to empower young people with intellectual disability.

What they told us

Firstly, many young people told us they felt left out of transition planning at school, with most decisions being made for them. There were limited, if any, opportunities for them to explore post-school options. As one participant said, "I don't want people that are, like, like, you know, just making choices for me."

Secondly, all participants found accessing NDIS funding complicated. They relied on parents or other advocates to navigate the process, to ask the right questions, and help with difficult jargon—or, as stated by one young person, knowing how to "bark the right way."

After leaving school, many felt lonely, lost and uncertain about their adult role and identity. Some felt "left behind" by friends and siblings without disability who had jobs and life partners, intimate relationships and were raising families of their own. "It's hard to find a partner [...] or to know someone and be with someone."

There was a shared sense among participants that most disability services did not prioritize activities to support reaching their goals. A young woman explained how finding a service with a good fit had been very difficult. She talked about how her first service provider had "tried to



like take us for money" without providing a service.

Other participants felt "stuck" with a life in disability services locked into the role of "disability person," while wanting to do and be more. "You know [...] I want to do some more in life and [...] I want to be out there. Know what I mean?"

Participants felt they needed better support with finding and keeping employment, even from agencies that had been contracted to do so. Getting help with finding a paid job seemed especially frustrating and out of reach. One young man called it a "total nightmare" explaining, "So they're basically, you know, not very well, um, structured [...] you're just waiting here for that lottery ticket to draw your name out."

The same goals as young people without disability

This study shows transition planning processes remain inconsistent and there is <u>insufficient collaboration</u> between school systems, adult disability services and the workforce.

Participants in our study had the same goals as young people without disability for meaningful work, independence and social connection—but need better support to contributing meaningfully to their communities.

The sense of "feeling stuck" with life in disability services or in "perpetual transition" may be caused by conflicting beliefs and values between service providers and consumers.

Young people expect to take on adult roles after leaving school. But disability service providers often see these young people merely as service receivers. Standardized processes and procedures may create "institutionalized identities".



The highly standardized nature of the NDIS leaves it inaccessible for people with intellectual disability, so the promise of choice and control in adult life is far from reality.

How it should be

Australia needs nationally consistent policies backed by systematic actions and oversight that truly supports the transition from <u>school</u> into meaningful adult lives for <u>young people</u> with intellectual disability.

People with disability must be actively involved in developing transition and service plans, with goals for growth and for moving between or beyond disability services once milestones are met.

Strategies must include steps for fostering social identities through friendships, casual to ongoing employment, <u>intimate relationships</u>, parenting or caring for others.

Further shifts in the NDIS model are also needed to foster individualized and supported planning for people with <u>intellectual disability</u>.

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