



DSA Submission
National Disability Employment Strategy
Consultation Paper

May 2021

About Down Syndrome Australia

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down Syndrome Australia is making this submission on behalf of its members. Down Syndrome Australia and its members work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome. We work in partnership to maximise the opportunities and support for people with Down syndrome and their families and support networks.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 13,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.¹

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¹ Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/>

Submission: National Disability Employment Strategy

Down Syndrome Australia (DSA) welcomes the opportunity to respond to the April 2021 National Disability Employment Strategy Consultation Paper. The paper proposes 4 key priority areas:

- 1) Lifting employer engagement capability and demand
- 2) Building employment skills, experience and confidence of young people with disability
- 3) Improving systems and services for jobseekers and employers
- 4) Changing community attitudes.

DSA supports the vision of the Strategy and proposed priority areas.

DSA is very concerned, however, that the Strategy does not acknowledge the additional barriers faced by people with intellectual disability and the need for specific strategies and supports to address these issues. We are also concerned that the Strategy continues to support the segregation of people with intellectual disability through Australian Disability Enterprises noting: “The ADE model... provides economic and social benefits to approximately 20,000 people with moderate to severe disability who face significant barriers to obtaining mainstream open employment.” At the same time the paper indicates that the development of the Employment Strategy “underscores Australia’s commitment to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), which recognises the right of persons with disability to work, on an equal basis with others.” These two statements are not consistent, as the ADE model does not support people with disabilities to work on an equal basis to others. The Employment Strategy is an opportunity to deliver on Australia’s commitment to the UNCRPD and develop new approaches to supporting people with intellectual disability to gain meaningful open employment at award wages, instead of further entrenching the existing system of segregation.

Intellectual Disability and Employment

The National Disability Employment Strategy must have specific actions to support people with intellectual disability to secure employment. The consultation paper noted “Research also indicates the vast majority of people with disability require no additional support in the workplace”. People with intellectual disabilities face additional difficulties in finding employment compared to people with other disabilities and in most case do require additional supports.

Recent figures collected by the Australian Bureau of Statistics² revealed that people with intellectual disability face a range of challenges in paid employment³, including:

² Australian Bureau of Statistics (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. <<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#children-with-disability>> (Accessed 10 March 2021)

³ Australian Bureau of Statistics. (2012). *Intellectual Disability, Australia, 2012*. <<https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4433.0.55.003main+features452012>> (Accessed 26 March 2021)

- People with an intellectual disability were less likely to be employed full-time (12%) than people with other types of disabilities (32%) and the population without disability (55%).
- Around 34% of people with intellectual disability found it difficult changing jobs or getting a preferred job, and about 38% felt they were restricted in the type of job they could get.
- Other difficulties surrounding employment included a restriction in the number of hours they were able to work (20%), needing time off work (13%) and needing ongoing assistance (17%).

Data from the NDIA (2018) found that only 33% of adults (25+) with an intellectual disability who were participants of the NDIS were employed. Only 3% adults with an intellectual disability were employed within open employment and paid full award wages. For people with Down syndrome, 34% of adults were employed, but only 2% were in open employment receiving an award wage. **Nearly 75% of people with intellectual disability who are employed are employed within segregated settings (Australian Disability Enterprises).**⁴

There is good evidence on how to tackle the barriers to open employment for people with intellectual disability. Inclusion Australia recently partnered with the Centre for Social Impact Swinburne to review the evidence on intellectual disability and open employment.⁵ The identified a range of factors that have a positive impact on employment outcomes for people with intellectual disability including:

- Work experience
- High expectations
- Support for transition
- Completion of secondary school
- Customised employment
- Individualised placement and support
- Mentoring
- Interagency collaboration

It is imperative that the National Disability Strategy acknowledges the specific barriers faced by people with intellectual disability and identify evidenced-based strategies to support people with intellectual disability in securing mainstream employment.

Australian Disability Enterprises and intellectual disability

As noted above, most people with intellectual disability who are in the workforce participate in segregated employment. Often they are told there are no other options. There are approximately 20,000 people working in ADEs and the majority of these have intellectual disability. ADEs often are cited as a way to build skills and provide the supports for people with disability to transition to open employment. But the reality is that very few people in ADEs will transition to open employment over the course of their career.

⁴ <<https://data.ndis.gov.au/media/1562/download>> (Accessed 26 March 2021)

⁵ Wilson, E. & Campaign, R. (2020). Fostering employment for people with intellectual disability: the evidence to date, Hawthorn, Centre for Social Impact, Swinburne University of Technology

According to the Department of Social Services (DSS), less than 1% of ADE participants transition to open employment in any given year.⁶ ADEs are not self-sufficient organisations. The average annual cost according to the DSS is \$11,800 per person, per year.⁷ The government committed another \$1.3 billion to support employees in ADEs from 2015 to 2020. As of 31 March, most of the funding for ADE's comes directly from NDIS packages. (The only exception is for employees of ADE's who are not eligible for the NDIS who continue to be supported through Department of Social Services).

It is concerning to see the consultation paper suggest that ADE's are a potential pathway for work experience for students with a disability. Given the success rates of transitioning to open employment, utilising ADE's for work experience means that these students do not get the chance to explore other options and are started down a pathway of segregation before they even officially enter the workforce.

Some families see a placement for their son or daughter in an ADE as the only option that enables them to continue their own employment or as a form of respite. When concerns have been raised about future sustainability of the ADE system, families question what people with intellectual disability will do if they are not able to work in open employment and they note how much the person values the social contact provided. People with Down syndrome often report feeling pride in having a job regardless of the setting. However, a segregated, subsidised employment system is not the answer to questions about respite or community engagement. Other countries that have moved away from segregated employment have found that other community-based activities including volunteer work, employment training and other involvement often lead to better outcomes than continued segregation in workplace settings.

For some, the move to NDIS has increased transparency about the ADE funding model. Many parents are shocked to learn that the workplace is taking more money from their package, than the person with the disability is earning. One recent example was given where the person with disability would receive \$17.50 for 5 hours of work, while the employer would receive \$309 per week from her NDIS package to provide support. Another example was given where the person earns \$25 per week for 11 hours of work, and the employer charges the NDIS \$243 per week for providing support. There was an outcry on social media when these stories were shared, with people urging families to make complaints to the Quality and Safety Commission. Many were surprised to learn that these were not dodgy providers, but instead is typical for how the ADE system operates.

The level of transparency provided by having funding for ADE's come directly from NDIS packages will likely mean that some people with intellectual disability and their families will identify other approaches to employment and support that provide greater cost-benefit to the individual with the disability. But often people with intellectual disability and their families are not aware of other options. The National Disability Strategy must include the development of a roadmap for transitioning out of segregated settings for employment.

Segregation is discrimination

People with intellectual disability have experienced historic institutionalism and continued segregation together with ongoing stigmatising and discriminatory attitudes, behaviours and systems. Unlike many

⁶ Australian Government, Department of Social Services, Discussion Paper. (December 2017). Ensuring a strong future for supported employment.

⁷ Australian Government, Department of Social Services, Discussion Paper (December 2017). Ensuring a strong future for supported employment, p. 12.

other types of disability, people with intellectual disability still face segregation within education, housing, and employment.

The National Disability Employment Strategy must acknowledge that segregation is a form of discrimination. The Disabled People's Organisations Australia Position Paper⁸ (the Position Paper) is supported by 42 disability rights and advocacy organisations (including Down Syndrome Australia) calling for an end to the segregation of disabled people in Australia. The Position Paper describes the separation of disabled people from the rest of the community 'by law, policy and practice frameworks that enable 'special' segregated arrangements'. The Position Paper notes that this separation is 'particularly the case for people with intellectual, cognitive or psychosocial disability, neurodivergent peoples, people with multiple impairments, and others who are warehoused in segregated settings and environments due to a lack of adequate services and supports'.

The Position Paper calls for six actions to end segregation (including segregated employment such as the ADE's). The first action includes ensuring that the human rights model of disability and the principles of equality and non-discrimination underpin the development, implementation and review of law, policy and practice frameworks through the provision of training and guidance to policy makers and legislators at all levels of government, to law reform bodies, to the Parliamentary Joint Committee on Human Rights and to the National Disability Insurance Agency (NDIA), the NDIS Commission and the Disability Royal Commission.

Evidence

There is strong evidence from both Australia and internationally that people with intellectual disability can work within open employment and that open employment leads to better outcomes than segregated employment.

Open employment leads to better outcomes

The benefits of open employment have been repeatedly demonstrated. For example, a study from the US found that people with intellectual disability who enter open employment and receive appropriate support had better employment outcomes (wages, hours worked) and equivalent length of time in employment re compared those who started in 'sheltered workshops'. It was also noted that this came at a lower cost to government⁹.

A number of studies have also examined the relationship between different types of work and quality of life. A recent UK study found that people with intellectual disability who participate in open employment had higher quality of life outcomes than those in segregated employment or day programs. They noted: 'supported employees in competitive employment reported better health, higher productivity and better emotional wellbeing than the people with intellectual disabilities in employment enterprises or day services.'¹⁰ An Australian study focusing on people with Down syndrome, found that the reported family quality of life was significantly higher for people with Down syndrome who were in open employment

⁸ The Disabled People's Organisations Australia Position Paper (2020) Segregations of People with Disability is Discrimination and must end, accessed 10 March 2021 <https://dpoa.org.au/wp-content/uploads/2020/11/Segregation-of-People-with-Disability_Position-Paper.pdf>

⁹ Cimeria, R. E. (2011). Does being in sheltered workshops improve the employment outcomes of supported employees with intellectual disabilities? *Journal of Vocational Rehabilitation*, 35(1), 21-27.

¹⁰ Beyer, S., Brown, T., Akandi, R., & Rapley, M. (2010). A comparison of quality of life outcomes for people with intellectual disabilities in supported employment, day services and employment enterprises. *Journal of Applied Research in Intellectual Disabilities*, 23(3), 290-295.

compared to those who were in segregated employment, controlling for other relevant factors.¹¹ Akkerman (2016) found that ‘the majority of people in competitive employment, who had previously worked in an employment enterprise, preferred their job in competitive employment.’¹² Migliore, Mank, Grossi and Rogan (2007)¹³ in their literature review summarise the advantages of competitive employment over segregated employment which include the following: better financial outcomes, increased opportunities for personal growth, compliance with the paradigm shift from fitting people into programs to adapting services to people’s needs, fulfilment of the preferences of people with disabilities, satisfaction of families’ preferences, and greater social inclusion.

Capacity to work in open employment

There is good evidence that with the right support, people with intellectual disability can participate in open employment. For example, Job Support, a specialist DES provider in NSW and Victoria, has had success in supporting people with intellectual disability (IQ<60) in open employment. Recent data from DSS suggests that they have a job placement rate of 83% with 81% of those placements lasting for one year or more. These results highlight the importance of specialist supports. Other DES providers who do not provide the specialist support required for people with intellectual disability have a much lower rate of success in supporting people with intellectual disability.

For this reason, it is essential that the Disability Employment Strategy include reforms of the DES system. DSA strongly supports the recommendation that the disability employment support system is reformed to focus more on jobseekers as individuals, considering their strengths, ability, rights and aspirations. It is essential that people with intellectual disability and their families have choice and control over their funded supports and are able to access providers that have the expertise in intellectual disability and employment that is required.

International experiences

One of the concerns cited by families is that without the option of segregated employment people with intellectual disability will have no opportunities for social engagement or meaningful employment. The experiences internationally do not support this view. In a number of countries, due to the commitment to the UNCRPD, there have been recent policy changes to reduce segregated employment. Findings from countries which have moved away from segregated employment suggests that often other community-based activities including volunteer work, employment training and other involvement lead to better outcomes than continued segregation in workplace settings.

For example, in the state of Vermont, the last sheltered workshop was closed in 2002. Approximately 50% of people with intellectual disability are now employed in open employment (compared with 3% in Australia). A number of universities in Vermont are now offering education programs that help get people ready for the workplace. Vermont is also one of the few states in the US that does not provide segregated day programs, but instead takes an inclusive approach to providing assistance to people to choose how and where they spend their day. People with intellectual disability who have not found open employment have

¹¹ Foley, K. R., Girdler, S., Downs, J., Jacoby, P., Bourke, J., Lennox, N., ... & Leonard, H. (2014). Relationship between family quality of life and day occupations of young people with Down syndrome. *Social psychiatry and psychiatric epidemiology*, 49(9), 1455-1465.

¹² Akkerman et al. (2016). Job satisfaction of people with intellectual disabilities in integrated and sheltered employment: an exploration of the literature. *Journal of Policy and Practice in Intellectual Disabilities*, 13(3), pp 205-16

¹³ Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26(1), pp 18-19

taken up roles as volunteers or get support to be involved in the community in other ways such as pursuing hobbies, becoming active in other community groups or spending time with family or friends.

Role of Education

It is also important to recognise the role that education settings can have on future employment opportunities. A recent international review¹⁴ found that a link between the type of education a student receives (segregated versus mainstream) and their future employment outcomes and social inclusion. Students who are included in mainstream schools are more likely to go on to mainstream employment. This review highlights the need for a lifelong approach and investment in community inclusion.

Conclusion

The National Disability Employment Strategy must include specific actions to address the barriers to open employment faced by people with intellectual disability. The Strategy is an opportunity for Australia to deliver on their commitment to the UNCRPD which states that people with a disability have the right to work on an equal basis to others. There is clear evidence that inclusive employment leads to better outcomes for people with disability, yet the majority of people with intellectual disability in Australia who are in the workforce participate in segregated employment due to a range of different reasons.

The National Disability Employment Strategy provides an opportunity to transition out of a segregated employment system and to provide opportunities for people with an intellectual disability to work in open employment. To be successful, the Strategy must include clear approaches against each of the 4 priorities that focus specifically on intellectual disability. These initiatives should be informed by the latest international evidence about the best approaches to support people with intellectual disability in open employment. Without this targeted approach, there is a risk that people with intellectual disability will miss out once again and this strategy will have little relevance or impact for people with intellectual disability.

¹⁴European Agency for Special Needs and Inclusive Education, 2018. Evidence of the Link Between Inclusive Education and Social Inclusion: A Review of the Literature. (S. Symeonidou, ed.). Odense, Denmark