

Position Paper on Employment

About Down Syndrome Australia

Down Syndrome Australia is 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. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

Purpose

The purpose of this paper is to set out Down Syndrome Australia's (DSA's) position on employment for people with Down syndrome. This is the position that will be the basis for DSA's advocacy to government for changes to the employment system in Australia. It also makes specific recommendations to improve access to open employment.

This document is focused on advocacy – not on providing advice on employment. Other information about employment is available on the DSA website. This includes resources for employers, employees, fact sheets and toolkits. These can be accessed at

https://www.downsyndrome.org.au/community_inclusion.html#employment

Summary

The UN Convention on the Rights of Persons with Disability (UNCRPD) says that Australia, as a signatory, must 'recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.' However, segregated work environments continue to be the most common work place settings for people with intellectual disability in Australia.¹

DSA argues that there is a need for a new approach to supporting people with intellectual disability to participate in employment. We know from international examples that it is possible to move away from segregated employment models and have good outcomes for people with intellectual disabilities.

DSA makes the following specific recommendations to government on employment for people with Down syndrome:

1. **An 'open employment first' approach to NDIS planning.** NDIS plans should include a focus on building skills to support transition to open employment. Funding for Australian Disability

¹ Tuckerman, P., Cain, P., Long, B., & Klarkowski, J. (2012). An exploration of trends in open employment in Australia since 1986. *Journal of Vocational Rehabilitation*, 37(3), 173-183.

Enterprises (ADEs) – also known as sheltered workshops – should only be considered after all other options have been explored including open employment, skill development, and volunteering opportunities. Participants should not be disadvantaged if they use NDIS supports to access employment instead of Disability Employment Services (DES) providers (e.g. having access to wage subsidies).

- Better support for the transition from school into open employment.** Often schools use ADEs as ‘work placements’ for students with intellectual disability. This limits their ability to develop workplace skills and to fully explore their options. Work experience should be provided within open employment for all students. Opportunities to access work experience should begin early (year 10) where possible. The NDIS School Leavers Employment Supports (SLES) also has an important role to play in assisting students who are moving into employment. As noted above, this funding should not be used to support transition into ADEs.
- Removal of barriers to accessing DES providers.** Only 4% of people supported by DES have an intellectual disability. Job capacity assessment is one of the major barriers for people with intellectual disability to access support through DES. Often the assessment does not take into account the potential of a person with intellectual disability when adequate support and training is provided, so it doesn’t provide the full picture. If the assessment indicates that the person has a ‘job capacity’ of less than eight hours per week, they are not eligible for support under the DES which leaves segregated employment as their only option. If someone is willing to work, and wanting to develop skills to make that occur, they should not be turned away from DES.
- Improved support for people with intellectual disability through DES.** This includes long-term support within the workplace, support for more specialised DES providers who work with people with intellectual disability, funding to DES to support the work needed to assist a person with intellectual disability. For example, DES providers should receive a financial incentive from government for accepting voluntary registrations from people with intellectual disability.
- Improvements in post-school educational pathways for people with intellectual disability.** There are a few examples in Australia of programs that provide educational pathways to employment. However these options are limited. Inaccessible curriculum design and assessment processes mean that people with Down syndrome are effectively shut out of vocational courses run by TAFEs. In some states there is also a lack of appropriate entry-level courses provided by TAFEs or RTOs.

Background

In Australia, there is a range of settings where people with intellectual disability participate in the workforce including:

- Open employment: where people with disability are working alongside other people who do not have a disability.
- Micro-enterprise: a very small business usually run by one person.
- Social enterprise: a for-profit business that also provides a social benefit to its staff and/or customers.

- Australian Disability Enterprises (ADEs): segregated work environments.
- Volunteer roles.
- Combinations of the above.

The majority of 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 approximately 75% 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. According to the Department of Social Services (DSS), less than 1% of ADE participants transition to open employment in any given year.²

ADEs are not self-sufficient organisations. The average annual cost according to the DSS is \$11,800 per person, per year.³ The government has already committed another \$1.3 billion to support employees in ADEs from 2015 to 2020. Consideration needs to be given to whether some of this funding could be used to support people with intellectual disability to access open employment.

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.

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.

Benefits of open employment

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

² Australian Government, Department of Social Services, Discussion Paper. (December 2017). *Ensuring a strong future for supported employment*.

³ Australian Government, Department of Social Services, Discussion Paper (December 2017). *Ensuring a strong future for supported employment*, p. 12.

compared those who started in 'sheltered workshops'. It was also noted that this came at a lower cost to government.⁴

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.'⁵ An Australian study which focused 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 compared to those who were in segregated employment, controlling for other relevant factors.⁶ 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.'⁷

Migliore, Mank, Grossi and Rogan (2007)⁸ 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.

People with intellectual disability have the 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 very good 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 at least one year or more. These results highlight the importance of specialist supports. Other DES providers who do not provide the specialist supports required for people with intellectual disability have a much lower rate of success in supporting people with intellectual disability.

⁴ Cimera, 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.

⁵ 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.

⁶ 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.

⁷ 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

⁸ 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

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 (twice the national average). 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 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.

In Australia, researchers found that families where the person with Down syndrome was in open employment said the family had a better quality of life than families of people working in sheltered employment. Also, people with disability who used to work in an ADE, told researchers they preferred their job in open employment⁹.

DSA position

People with disability have the right to work on an equal basis with others including to work within open employment. This right is outlined in the UNCRPD (of which Australia is a signatory). 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.

As a systemic advocacy organisation, we work to achieve policy changes which support the human rights of people with Down syndrome. For this reason, we advocate for people with Down syndrome to have choices about where they work, including to work within open employment.

DSA does not take any position on individual decisions about employment. DSA acknowledges that some people choose segregated employment settings and they do so for a number of different reasons. Many people with intellectual disability value the friendships and social connections that they make within those settings. Often ADEs are seen as the only employment options that are available. People face barriers to

⁹ 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.

open employment due to job capacity testing for DES, as well as a lack of employers who understand and are willing to make appropriate accommodations. There is a need for support for both the person and the employer.

Down Syndrome Australia believes that there is need for reform to the disability and employment sector, particularly for people with intellectual disabilities. This reform must be guided by a human rights approach and a focus on inclusion in the workplace and the broader community. The full implementation of the NDIS provides an opportunity to trial new models of employment and support, and to develop each community's capacity to provide local employment opportunities.

Down Syndrome Australia does not believe the current system of ADEs provide the best options for people with disability. We are not, however, advocating for the closure of ADEs. Instead, we believe that by improving pathways to open employment and providing the right supports and information, we will see a transformation of the sector. If NDIS planners focus on supporting people to find opportunities within open employment and the community, there will be a natural move away from the segregated model of employment without creating unneeded disruption.

The reforms required include:

1. **An 'open employment first' approach to NDIS planning.** NDIS plans should include a focus on building skills to support transition to open employment. Funding for Australian Disability Enterprises (ADEs) – also known as sheltered workshops – should only be considered after all other options have been explored including open employment, skill development, and volunteering opportunities. Participants should not be disadvantaged if they use NDIS supports to access employment instead of Disability Employment Services (DES) providers (e.g. having access to wage subsidies).
2. **Better support for the transition from school into open employment.** Often schools use ADEs as 'work placements' for students with intellectual disability. This limits their ability to develop workplace skills and to fully explore their options. Work experience should be provided within open employment for all students. Opportunities to access work experience should begin early (year 10) where possible. The NDIS School Leavers Employment Supports (SLES) also has an important role to play in assisting students who are moving into employment. As noted above, this funding should not be used to support transition into ADEs.
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4. **Improved support for people with intellectual disability through DES.** This includes long-term support within the workplace, support for more specialised DES providers who work with people with intellectual disability, funding to DES to support the work needed to assist a person with intellectual disability. For example, DES providers should receive a financial incentive from government for accepting voluntary registrations from people with intellectual disability.
5. **Improvements in post-school educational pathways for people with intellectual disability.** There are a few examples in Australia of programs that provide educational pathways to employment. However these options are limited. Inaccessible curriculum design and assessment processes mean that people with Down syndrome are effectively shut out of vocational courses run by TAFEs. In some states there is also a lack of appropriate entry-level courses provided by TAFEs or RTOs.