



Down Syndrome Australia Submission

New Disability Employment Support Model

December 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: New Disability Employment Support Model

Down Syndrome Australia (DSA) welcomes the opportunity to provide input into the New Disability Employment Support model being developed by Department of Social Services. Our response focuses on key issues for people with Down syndrome and their families.

We would like to note the short time frame for the consultation period and the difficulty this has posed in consulting with our membership on this key issue. There is also concern that the timeline is too short to enable reform of the DES program prior to the start of new contracts. We look forward to participating and supporting our members to participate in the workshops held next year by PwC to provide further input. Consideration should be given to trial different service delivery models with a focus on best-practice, evidenced based supports.

It is essential that the new disability employment support model consider the specific needs of people with intellectual disability in accessing paid employment.

Recent figures collected by the Australian Bureau of Statistics² revealed that:

- 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.

Data from the NDIA (2020) found that only 29.5% of adults (25+) with an intellectual disability who were participants of the NDIS were employed. For people with Down syndrome, 32% of adults were employed, but only 2.5% were in open employment receiving an award wage. **72% of people with Down syndrome who are employed are employed within segregated settings (Australian Disability Enterprises).**³

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 compared those who started in 'sheltered workshops'. It was also noted that this came at a lower cost to government⁴.

Several 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

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<https://data.ndis.gov.au/media/2815/download?attachment> <accessed 16/12/21>

⁴ Cimer, 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.

emotional wellbeing than the people with intellectual disabilities in employment enterprises or day services.⁵

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 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.

It is imperative that the New Disability Employment Support Model acknowledges the specific barriers faced by people with intellectual disability in accessing open employment and identifies evidenced-based strategies to support people with intellectual disability in securing mainstream employment.

The disability employment support system must be 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 can access providers that have the expertise in intellectual disability and employment that is required. There is a need to ensure that the DES program is closely aligned to employment supports through NDIS and that there are no gaps between the two approaches to providing employment supports. This new DES program must be holistic and allow for people with Down syndrome to continue in their career over the course of their working life by where the program allows for easy re-access to DES when support is needed.

Access

People with intellectual disability are under-represented in the DES Services. According to Appendix 2 in the consultation paper, only 3.1% of DES users have an intellectual disability. In comparison, 20% of NDIS participants have an intellectual disability. One of the barriers to access DES for people with intellectual disability is the requirement for DES participants to be assessed as having a minimum work capacity of 8 hours. If you are assessed as only being able to work less than 8 hours in open employment, you are only offered support to work at an ADE. We also have anecdotal reports from members that in some cases people with an intellectual disability are turned away from DES without an assessment of capacity but because of an assumption that is made by the provider. The requirement to meet assessed capacity of 8 hours should be removed, and anyone who wishes to use the service should be able to access it.

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

The proposed idea of providing a range of employment/engagement pathways which could include community engagement, volunteering, and casual work could be beneficial for people with intellectual disability. Providing these options would be a way for some people with intellectual disability to develop skills, have opportunities for participation and a pathway for future work. If employment supports are expanded beyond traditional workplaces, care must be taken that employees are not exploited (e.g., asking to volunteer for a role that people without disability do in a paid capacity), or that this is being done at the expense of access to meaningful employment.

Employment supports could also include participation at TAFE/university. Many young people after they leave school will attend TAFE/university for further education to have the qualifications for a particular job, but also to learn other important skills that will benefit them in the workplace. People with intellectual disability face significant barriers to engaging in TAFE/university, as these systems are not currently inclusive, nor do they offer supports or programs for PWDS/PWID to participate.

There is a need for better integration across NDIS and the Disability Employment Supports provided through DES. There is limited transition from SLES to DES and the two schemes operate separately.

In most cases the DES system is not providing appropriate support for individuals with Down syndrome or intellectual disability. In many cases, having employment supports including in an NDIS plan can provide the more tailored support required by people with intellectual disability, including support to work with an employer on job-carving.

Entry/Assessment Disability Employment Support

People with an intellectual disability need a simple and effective way to get support for employment that is tailored to their needs. As outlined above, the work assessment process often limits access to DES for people with intellectual disability due to their assessment of the number of hours someone can work.

The focus of assessment should move from work capacity in terms of hours to assessing the strengths and abilities of the person with disability. This information should then be used to provide tailored support and connecting the person to employment that will match their needs. Assessment from relevant qualified professionals (e.g., OT, psychologists) could assist in providing more meaningful assessments that can be utilised to provide the supports people require.

Linking provider payments based on achieving outcomes that match assessed work capacity is also problematic. Capacity can change over time and can be dependent on the supports that are available. The assessment process should also allow for different assessments at different stages of the work journey. This will enable an acknowledgement of what people with disability can learn and achieve after they have had an opportunity to practice skills or gain confidence.

Improving Services and Supports for people with Intellectual disability

The DES system in most cases does not provide appropriate supports for people with intellectual disability or Down syndrome. There are a small number of providers who specialise in intellectual disability who have better outcomes in supporting people in open employment. Job Support, a specialist DES provider in NSW, Queensland, 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.

Research has shown the importance of job-carving, or customised employment in supporting people with intellectual disability to gain and retain employment⁹. Working with employers to identify opportunities and to create jobs which are suitable for people with intellectual disability can take significant time, expertise, and resourcing. Often DES providers try to fit clients into existing roles which do not appropriately match their skills and abilities. DES providers are also not motivated to support people with a disability who want to change jobs. In the modern environment, people change roles every 2-3 years and people with a disability should be supported to make these transitions as well.

Down Syndrome Australia is currently funded through ILC for the 'Right to Work' program. This program is still in the early stages but includes a program for people with Down syndrome to assist them in developing work readiness skills, as well as a network of 'Business Connectors' who work to connect people with Down syndrome to employment. These Business Connectors also upskill interested employers in how to best provide support to a person with Down syndrome. In some cases, the Business Connectors are also working with DES providers who provide longer-term support within the workplace. This model of short-term intensive tailored support by specialists who work in collaboration with the DES provider addresses several key barriers faced by people with intellectual disability in the DES system.

This specialist approach could be implemented by providing people with intellectual disability who are seeking employment with short-term funding that they can use to access specialist support. It is essential that this support is then linking in with a DES who can provide the ongoing support to the employee and employer once a position has been established.

The NDIS currently offers a capacity to purchase needed employment supports, for those who are eligible, but there is no clear mechanism around the delivery of evidenced-based supports. There is a need to develop and support ongoing programs of evidence-based employment supports, rather than ad-hoc funding through grants such as the ILC program.

People with intellectual disability who are successful in retaining employment often have regular support from an engaged DES provider and they also often have an engaged mentor within the workplace. This mentor can sometimes pick up on small issues and either address these or draw them to the attention of the DES worker so that potential problems are worked on before they become major issues.

In regard to transition between education and employment, it is essential for students with a disability to have opportunities to develop foundational skills and knowledge around employment, including through meaningful work experience opportunities. Students should receive support in considering employment pathways before they finish school.

Supports for Employers

There is extensive evidence that many employers are not confident that they have the knowledge or understanding on how to employ a person with a disability. This is particularly true for employing a person

⁹ <https://www.everyonecanwork.org.au/wp-content/uploads/2020/11/Fostering-employment-for-people-with-intellectual-disability-Accessible.pdf>

with an intellectual disability. Many employers are not aware of the support available through DES or JobAccess.

The 'Right to Work' program being delivered by Down Syndrome Australia is an example of how employers can be supported with specialist information to assist in their recruitment of a person with a disability. This tailored approach for employers can address some of the barriers currently experienced. It can provide information about the benefits employment of a person with a disability can bring both to the person and the workplace.

Driving high quality services and supports

Providing people with more choice and control over the services they receive will be beneficial. For example, utilising the NDIS model where people are allocated funding and can choose how they use that funding to meet their goals would assist in driving performance of providers.

In addition, there needs to be clearer measurements of outcomes that are meaningful to people with a disability. Currently outcomes are only reported in terms of job placement and retention. Data should be made publicly available about the experience of clients including their experience with the job placement, satisfaction with the support they received, and information about why the placement did not work out. In addition, longer term outcomes should also be reported (job retention for more than 12 months).

Summary

It is essential that the new disability employment support model consider the specific needs of people with intellectual disability in accessing paid employment. People with intellectual disability have worse outcomes in terms of access to open employment and award wages. Data from NDIA indicates that only 2.5% of adults with Down syndrome are in open employment. It is imperative that the New Disability Employment Support Model acknowledges the specific barriers faced by people with intellectual disability in accessing open employment and identifies evidenced-based strategies to support people with intellectual disability in securing mainstream employment.