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## **Submission to the Supported Employment Inquiry**

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## 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. 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.

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 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.<sup>1</sup>

Down syndrome is the most common cause of intellectual disability and everyone who has Down syndrome will have some degree of intellectual disability. In the past, many people with Down syndrome have not had the same opportunities as their peers. Often, they have been separated from the rest of the community, living in segregated settings such as care institutions. Low expectations were placed on them and there were limited opportunities for learning and participation in inclusive activities.

With better early intervention and medical care, as well as the increased inclusion and integration of people with Down syndrome into society, the quality of life for people with Down syndrome has increased. Children with Down syndrome often attend childcare settings, pre-schools and primary and high schools alongside other children of their age. Adults with Down syndrome are involved in their communities including through paid employment (open or supported) and voluntary work. An increasing number are living independently, with some level of support, within the community. The life expectancy of a person with Down syndrome has increased from only 25 years of age in 1983 to approximately 60 years in 2016 due to better support and health care, with one in 1 in 10 living to their seventies.<sup>2</sup>

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<sup>1</sup> [http://www.downsyndrome.org.au/down\\_syndrome\\_population\\_statistics.html](http://www.downsyndrome.org.au/down_syndrome_population_statistics.html)

<sup>2</sup> Torr J, Strydom A, Patti P, Jokinen N. Aging in Down syndrome: Morbidity and mortality. *Journal of Policy and Practice in Intellectual Disabilities*. 2010;7(1):70-81.

## Submission to Department of Social Services on Supported Employment

Down Syndrome Australia welcomes the opportunity to provide a submission to the Department of Social Services consultation on Supported Employment. Our response focuses on employment for people with Down syndrome.

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.” The Department’s discussion paper states the Australian Government is committed to its obligations under the UNCRPD to provide, support and enable the rights of people with disability regarding equitable access to work. However, the commitment in the discussion paper fails to include the other key aspects of the Convention’s requirements regarding employment; that of having the right to work in the open labour market and gain a living. This selective use of the UNCRPD’s requirements to support the continuation of supported work environments is inappropriate.

In Australia, segregated work environments continue to be the most common work place settings for people with an intellectual disability.<sup>3</sup> As noted in the discussion paper, there are approximately 20,000 people working in ADEs and approximately 75% of these have an intellectual disability. Often segregated work environments are rationalised as a way of providing an opportunity to learn job skills and transition to open employment, as is done in the discussion paper. However, as the discussion paper also notes, very few people transition out of an ADE into open employment. There is little if any focus in most ADEs on transition to open employment, and until quite recently when concurrency of placements in ADEs and DES became possible, there was the very real disincentive that people had to give up their secure placements in an ADE to go onto a waiting list for a DES provider. Even now, such an opportunity is not well supported by providers and it isn’t generally promoted to supported employees.

ADE’s have also been seen by some families as the only option that ensures their son or daughter has a placement 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 an 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. However, a segregated, subsidised employment system is not an answer to questions about respite or community engagement. Findings from other 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 an intellectual disability are now employed in open employment (twice the national

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<sup>3</sup> 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.

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.

Research reveals that segregated employment often leads to worse employment outcomes than integrated employment. A study from the US found that people with an intellectual disability who enter integrated employment and receive appropriate support had better employment outcomes (wages, hours worked) and equivalent length of time in employment compared to those who started in “sheltered workshops”. It was also noted that this came at a lower cost to Government.<sup>4</sup>

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 an intellectual disability who participate in integrated employment had higher quality of life outcomes than those in segregated employment or day programs.<sup>5</sup> 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.<sup>6</sup>

In a number of countries, due to the commitment to the UNCRPD, there have been recent policy changes to reduce segregated employment. For example, in the United States, Medicaid has now specified that they will only provide funding to support “sheltered-workshops” that provide time-limited vocational support. Different State Governments have implemented this rule in different ways, and the Department of Justice has taken action against States who have not complied. For example, in 2012, a lawsuit was filed against the state of Oregon, saying that Oregon was unnecessarily segregating people in “sheltered workshops” and not giving them opportunities to work in integrated community settings. This claim was investigated and it was concluded that Oregon was indeed unnecessarily segregating people with disabilities and that they needed to move toward more community-based employment opportunities and reduce their reliance on “sheltered workshops”.

The discussion paper provided by the Department of Social Services focuses on continued support for a segregated approach to employment, an approach that its own figures show is not successful in engaging people in the workforce nor supporting people to move to open employment, and an approach that keeps people, primarily those with intellectual disability, poor, dependant on welfare and on their families (when

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<sup>4</sup> 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.

<sup>5</sup> 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.

<sup>6</sup> 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.

they have them) throughout their lives. The discussion paper, despite the UNCRPD, does not provide a strategy or vision for protecting the rights of people with a disability to work in an inclusive environment. Further work needs to be done to ensure that people with a disability get the opportunity to develop the skills and supports they need in order to work in an inclusive work environment. Too often, ADE's are the stopping ground and little support is provided for those who want to transition to open employment.

It is clear that reform of disability employment in Australia is needed. Australia's National Disability Strategy states that "Work is essential to an individual's economic security and is important to achieving social inclusion. Employment contributes to physical and mental health, personal wellbeing and sense of identity". Yet Australia ranks 21<sup>st</sup> out of 29 OECD countries when it comes to the employment of people with disabilities.

Australians with an intellectual disability have difficulty finding employment. The Survey of Disabilities and Carers (SDAC) found that only 39% of people with an intellectual disability are either working or looking for work, compared with 55% of people with other disabilities and 83% of the general population<sup>7</sup>. In addition, people with intellectual disability who do have a job only work an average of nine hours a week. Many of the people who are employed are working within ADE's and receiving less than minimum wage (average total annual wage is \$6,329). This is less than the average cost to Government to subsidise ADE's for their employment of the person (\$11,800).<sup>8</sup> In addition, due to their low wages, most workers in supported workplaces don't have the opportunity to build any savings for the future through superannuation contributions.

There are no publicly available Government employment statistics specific to people with Down syndrome; however, the national survey carried out by Down Syndrome Australia<sup>9</sup> in 2017 confirmed that people with Down syndrome experience very low levels of employment. The data showed that 23% of people with Down syndrome surveyed had no employment at all, 33% said they did volunteer work, 23% said they were in open employment, 35% were in sheltered/supported employment and 3% were self-employed. 51% of people received a 'supported wage', 15% said they received an award wage and 33% said they received no wage. The survey also showed that most people with Down syndrome receive little or no income, even when they are working, due to wage systems in Australian Disability Enterprises, minimal working hours or being employed as a volunteer.

People with Down syndrome want to work, and they are able to work. They and their families say they are concerned about the lack of vocational training and employment choices and frustrated by the types of work, pay and conditions in supported employment settings. Societal beliefs and attitudes are a major barrier, with many in the community still not understanding that people with intellectual disability can work in real jobs and contribute to the workforce. It is positive to hear of an initiative by Government to promote case studies of employment success within open employment. Further work needs to be done to market to potential employers the benefits of employing people with an intellectual disability.

<sup>7</sup> ABS. 4433.0.55.003 - Intellectual Disability, Australia, 2012

<sup>8</sup> DSS (2017). Ensuring a strong future for supported employment

<sup>9</sup> Down Syndrome Australia (2017). National Survey. (*unpublished*).

It is also clear that the current employment support systems are just not working for people with intellectual disability; DES programs simply aren't resourced to help people who may need more and ongoing support, leaving people with few options.

There is a need for a new approach to supporting people with an intellectual disability to participate in employment. The NDIS provides an opportunity to trial different ways of supporting engagement in open employment as well as other forms of participation within the community. Indeed, the huge changes being brought about by the NDIS offers a once in a generation opportunity to look beyond current employment support structures and processes to a new paradigm. The recent McGarrigle case highlighted the cost of transporting people to supported employment some distance from their home. While we are not suggesting that people such as Mr McGarrigle be made to change workplaces, the case should surely be a catalyst for the government to consider what is needed to ensure future workers with intellectual disability have real, open employment opportunities in or near their own community, instead of propping up an unsuccessful system that segregates and disadvantages people throughout their lives. We suggest some strategies in this submission, but also ask that the government better resource the components of the NDIS and other government strategies to focus on community development to create greater inclusion of all community members.

There also needs to be consideration of how to improve incentives for businesses to employ people with an intellectual disability. Given the level of unemployment and long-term use of segregated work environments, action is required. One option would be through direct incentives to businesses.

For example, Restart is a program which provides businesses with a payment of \$10,000 for employing workers over the age of 50. This approach was released in 2014 along with an advertising campaign to promote the benefits of employing older workers. There are similar schemes available for Indigenous Australians, long-term unemployed and parents moving back into the workforce.

A similar approach could be taken to employment of people with an intellectual disability. The funding could be used to provide additional supports within the workplace, such as a mentoring program.

Below we provide our response to the specific questions which were identified in the discussion paper.

### Are there other principles, which should guide the Government's policy direction for supported employment?

Government policy direction on employment for people with a disability should be focused on protecting the rights of people with a disability to access inclusive and accessible employment, as specified by the UNCRPD. It is inappropriate for the Government to focus on the sustainability of a specific model of supported employment, the Australian Disability Enterprises, which is a segregated approach to employment. It is disappointing that questions are not asked around the benefits of transition to open employment.

*“I have worked in open employment for more than thirty years. I liked my job. The best part of working was the people. The best part would have to be knowing I was no different from anyone else. I was included” – person with Down syndrome*

*“I work in regular employment. I like being like everyone else, being paid like everyone else. Taking pride in doing the right thing.” – person with Down syndrome*

Without action to develop new models of support and to improve incentives for Disability Employment Services (DES) to work with people with an intellectual disability, we will continue to see segregated employment be the main option for employment of people with an intellectual disability. Often DES providers indicate that they do not have the financial support or staff with appropriate skills to support job placement for people with an intellectual disability. The implementation of the NDIS provides an opportunity for full-scale change in how employment supports are provided.

In moving away from segregated employment, additional supports would need to be put in place. For people who may not be able to be employed initially in open employment there needs to be a range of other options which are promoted including supported volunteer work, job training, and other ways of being involved in the broader community. There should also be a range of incentives put in place for mainstream businesses to employ a person with an intellectual disability. As noted above, such incentive approaches already exist for mature age workers, and parents transitioning back to employment. A similar approach could be implemented for intellectual disability.

The decision to include “Strong and Viable ADE’s” as a principle to guide Government policy also undermines the principle of choice which guides the NDIS. If people with a disability choose not to support an ADE model, then Government policy should not be supporting an approach which is not meeting the needs of people with a disability. Instead there should be a specific principle which focuses on supporting inclusive work practices and environment and enabling individuals to transition from segregated work practices.

The proposed principle of “An ‘employment first’ approach for all NDIS participants of working age” should be amended to an “integrated/open employment first or community engagement”. If an NDIS participant is unable to participate in open employment, supports should be put in place to work towards that goal or to find other ways of participating in the community. It is important to acknowledge the diversity of contributions to our community both within and outside of a formal workplace that all members of our community make including those with intellectual disability.

## What is a ‘good’ participation outcome for a supported employee and how can good outcomes be measured?

Outcome measurement for supported employment should include:

- Goal Attainment (measured through Goal Attainment Scale or similar methodology)
- Skill development

- Employment in an integrated setting
- Quality of life
- Social participation
- Time spent in employment

'Good' participation outcome would be where a person has developed new skills and capacity, has been provided with relevant job training, and skill development. Each person will have their own goals around employment and potential barriers to open employment. It is essential that these barriers are identified and relevant goals are developed. Good outcomes will depend on each individual and their work towards achieving their goals.

Supported employment should encourage the development of independence and provide the needed supports for the person with a disability. This is not happening at the moment, as evidenced by the very low rates of transition from supported to open employment.

### What do supported employees most value about working in an ADE?

Feedback from our members suggests that employees value the opportunity to make friendships and engage socially with other employees. They also take pride in having a job and feeling that they are contributing through the workplace. Families value the person having "somewhere to go" during the day and something constructive to do with their time.

It should be noted that the things that are valued within the ADE in most cases could be achieved through opportunities to be involved in the community or within open employment. Often people feel that these opportunities are not available to them or may not be as regular as involvement in the ADE. This highlights the barriers that people with a disability face in the community, but segregated workplaces only perpetuates a lack of inclusion. For example, there needs to be support for improving opportunities for social relationships outside the ADE.

There were also concerns expressed by some people about their experiences working within an ADE. These included not enjoying repetitive work, concerns about unfair pay, or feeling bored. Others felt that they weren't given the opportunity to learn the skills they needed to get the job they really wanted.

### How can more supported employees be provided the opportunity to choose open employment?

There are a number of strategies which should be put in place to improve the opportunity to be involved in open employment.

First, there needs to be a shift in expectations for people with an intellectual disability. It is often assumed by schools, parents and the broader community that people with an intellectual disability will not be able to have a job in open employment. This is due to historical beliefs, the low expectations of society, and the existing government systems that perpetuate these assumptions and lack of support for open employment, not on the reality of people's capacity. It is essential that the starting point for discussions about work is



how to support a person to participate in an integrated work setting, rather than presuming they will spend a lifetime working in a segregated workplace such as an ADE.

As part of this there needs to be better support around transition from school into open employment. Often schools use ADE's as 'work placements' for students with an 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. The NDIS School Leavers Employment Supports (SLES) also has an important role to play in assisting students who are moving into employment. Unfortunately, in some cases this funding is used to support transition into ADE's. This should not be allowed within the funding guidelines.

Often families are looking for something that will provide a smooth transition from school with minimal disruption to their working life or other commitments. Families who do not take up the ADE option often find themselves having to take on a larger role in terms of coordination, advocacy and transportation. The DES process can take a long time, often years, before an appropriate placement is found, and then due to inadequate levels of support possible from a DES, it may not continue for long, and so the cycle continues. Often the ongoing need for coordination and having a son or daughter at home during the day means parents giving up their own jobs. When one of the key roles of the NDIS is to help both people with disability and their family carers into the workforce, it isn't logical to have an employment support system that has quite the opposite effect for so many families.

There is also a parental/carer concern that if an offer of placement is not taken up then they may not get a second chance. There is also a reluctance to exceed 8-9 hours paid employment per week due to impact on DSP, particularly if the increase in hours does not work out and trying to reinstate any reduction in DSP. There needs to be consideration of providing a trial period within employment before DSP is reduced and information to parents on how DSP can be reinstated if employment does not continue.

There also needs to be improved support for people with intellectual disability through Disability Employment Services (DES). It was noted in the discussion paper that only 5% of people supported by DES have an intellectual disability. Job capacity assessment is often one of the major barriers to getting support through DES for people with an intellectual disability. Often the assessment does not provide a full picture of the potential of a person with intellectual disability if they were provided with adequate support and training. If the assessment indicates that the person has a "job capacity" of less than 8 hours per week, they are not eligible for support under the DES, suggesting their main option is segregated employment. If someone is willing to work, and wanting to develop skills to make that occur, they should not be turned away from DES.

For people with an intellectual disability there needs to be other changes to improve the supports that DES can provide. This includes needing long-term support within the workplace, specialised DES providers who work with people with moderate intellectual disability, funding to DES to support the work needed to assist a person with an intellectual disability.

For example, DES providers should be given a financial incentive for accepting voluntary registrations from people with intellectual disability. Currently, there is no incentive for a DES to provide the longer term, full onsite support for the high percentage of individuals with an intellectual disability in supported employment that could, given the appropriate support to themselves and employers, achieve a successful outcome. A flow on outcome payment to ADE's when open employment is achieved for an individual may support ADEs to encourage participants to engage with a DES.

JobSupport, a specialised DES provider in NSW which works mainly with people with moderate intellectual disability has shown very good results in finding employment through a proactive approach including job-matching (including job-carving), job analysis, training within the workplace, and ongoing support. As a result of this approach, their average job tenure is 7.2 years. Given their success, this specialised approach to providing DES to people with moderate intellectual disability should be replicated across Australia.

One of our organisations has had success in working closely with a large company in a pro-active recruitment process. The company provided a job description and worked with the Down syndrome organisation to carve out a number of part time jobs that would be suitable. The Down syndrome organisation provided advice, mentoring and training. As a result, two people with Down syndrome have been successfully employed on a part-time basis. Other companies have been approached and have expressed interest in employing people with Down syndrome with this support.

*We have been working with a DES for a number of years. They have been hopeless in finding real employment. They think he should just work in an ADE. They don't care, don't try and they have no idea. They say they don't have enough funding. They also just don't understand his needs.*

*-parent of adult with Down syndrome.*

People with an intellectual disability also need access to other approaches to community participation. A number of families have told us about the value of different types of community participation for adults with Down syndrome including supported volunteering, participating in the arts, and other community programs. Some families found it difficult to get support in these alternative approaches and others have been successful in utilising NDIS funding to support community engagement. The value of these alternate streams to community participation must be acknowledged and supported going forward.

Further work needs to be done on continuing education pathways as well. For example, the Uni2Beyond program at University of Sydney supports people with intellectual disability to experience university life at the University of Sydney. Students attend lectures of their choice as audit students, and participate in university social life through engagement with their peers. This program is providing a pathway to further independence and education. Similarly, other programs, such as Project21 in the Northern Territory provides an educational transition pathway into a work program. Other further education options are also extremely limited; inaccessible curriculum design and assessment processes as well as lack of appropriate courses mean that people with Down syndrome are effectively shut out of vocational courses run by TAFEs. Some of our state organisations are working to address these barriers to open employment.

*Support whilst at school was wonderful but has been less than wonderful since finishing school. It has been very difficult to find a service to support my son to access work in a voluntary capacity. He doesn't want to just work with people who have an intellectual disability like him. He wants to be part of the rest of the world just like the rest of us.*

-Parent of a young adult with Down syndrome

All employees need support, but support for employees with intellectual disabilities is more obvious and needs specific consideration. So, there needs to be improved support for employers to put in place appropriate strategies for the employment of a person with an intellectual disability. This includes training and information on different ways to support a person with Down syndrome as well as ideas about job sharing or job carving. Down Syndrome Australia, with ILC funding, is currently developing a toolkit for employers on employment of people with Down syndrome.

*The success of employment depends so much on the understanding of the employer and other employees. It is not enough for only the employer to be supportive - it takes a village to raise a child. Training & information/strategies need to be given to the entire workplace so there is a common understanding of the person's capabilities, strategies to help them optimise the workplace experience.*

-parent of adult with Down syndrome

*There needs to be guidelines for good communication strategies, problem solving strategies, programmes to develop a good working ethic and encouraging safety, security and support in the workplace.*

-Person with Down syndrome

## What is the role a supported employer can play in building employee capacity for transition to open employment?

The main roles of ADE's should be around supporting people with a disability to develop the skills they need to enter into open employment and supporting them to find placements within open employment. Unfortunately, currently there are not sufficient incentives for ADE providers to do this work.

One possible approach would be for ADE's to provide a time-limited apprenticeship (e.g. 2 years) which focused on providing training on job skills and independence. There needs to be a program of skill development and career progress within the ADE. Each employee should have an individual training and development plan which identifies their skills and areas where they need more support. A 6-monthly updated plan should identify the goals for the employee and ways in which the employer can assist the employee in meeting those goals.

After the two-year apprenticeship is completed, there should be a focus on transition to open employment and assisting the person in finding an appropriate job placement. There then needs to be a source of ongoing support to help people keep those jobs.

## How can the NDIS enable an employment first approach in planning?

As previously noted, it is the view of DSA that an employment first approach to planning is not always appropriate. NDIS should support a focus on creating inclusion in the community rather than on segregated services. For some individuals, community engagement or volunteering may be a more appropriate focus rather than employment. When employment is a key goal, NDIS planners should be well trained on employment supports and pathways to open employment, particularly for people with an intellectual disability. Options for that support should be discussed early in the planning process and case studies and examples of employment pathways should be provided by NDIA. It is important that NDIA planning not utilise ADE's as a form of respite where someone is unable to work in open employment.

## Summary

Down Syndrome Australia acknowledges that there is need for reform to the disability and employment sector, particularly for people with intellectual disabilities. The current level of employment for people with intellectual disabilities in Australia is very low. 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. It would be disappointing, and a betrayal of people's rights under the CRPD, if Government focused on ensuring the viability of old models instead of working to move away from segregated models of employment.

Disability Employment Services need to be provided with incentives to increase their work with people who have an intellectual disability. As the sector starts to transition, ADE's need to be required to provide individualised goal setting and skill development to assist in preparing individuals for open employment. There also needs to be a consideration of how people are best supported who may not be able to find open employment including through other approaches to community engagement outside of a workplace.