

# DOWN SYNDROME AUSTRALIA

Submission to Department of Social Services:  
Disability Employment Services Reform

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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, provide a national profile and voice for people living with Down syndrome, and to build resources and knowledge capacity of the state and territory Down syndrome associations. 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 (also known as trisomy 21) is a genetic condition in which the person has an extra copy 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. This is lower than the worldwide average of 1 in 700 babies due to higher termination rates in Australia.<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 DS into society, the quality of life with DS 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 voluntary work and employment. An increasing number are living independently, with some level of support, within the community.

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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)

## GENERAL COMMENTS

Down Syndrome Australia welcomes the opportunity to provide feedback to the Department of Social Services (DSS) in response to the 'New Disability Employment Services from 2018' discussion paper and to assist with the Department's consideration of Disability Employment Service (DES) reform. This submission will primarily focus on the specific issues facing people with Down Syndrome who are seeking employment. Down Syndrome Australia has also provided input to the submission developed by the Australian Federation of Disability Organisations (AFDO) which provides broader input on the proposed reforms.

Disability Employment Services provide an important support to people with a disability in entering open employment. This support is much needed as we know that people with disabilities can have difficulty accessing open employment and only approximately half of people with a disability are currently in the labour force.

It is important that any consideration of disability employment reforms takes into account the needs of people with intellectual disabilities. There are stark differences within disability groups in terms of employment outcomes. For people with intellectual disabilities access to employment can be more difficult. Evidence from the ABS Survey of Disability and Carers suggests that people with intellectual disability have worse employment outcomes<sup>2</sup> than other disability groups including:

- Higher rates of not being in the labour force (60% vs 50% for those with other disabilities and 18% for people without disabilities)
- Amongst those in the labour force- Being less likely to have full time employment (12% compared to 32% for those with other disabilities)
- Higher rates of unemployment (20% vs 8% for those with other disabilities)

Research from UNSW suggests that there are a range of barriers for people with intellectual disabilities in engaging and maintaining open employment<sup>3</sup>. These include

- Lack of funding/support for upskilling and education opportunities
- Difficulty with the application process
- Attitudes of employers
- DES not considering preferences for types of work
- Unstable labour market- people with intellectual disability were working in entry-level and/or low-skilled positions and as a result were more vulnerable to turnover and lack of clear employment pathways.

With appropriate support, however, many people with an intellectual disability find meaningful and engaging employment that supports their quality of life. It is essential that the Government work to ensure access to appropriate supports, addressing stigma and attitudinal issues.

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<sup>2</sup> ABS 4433.0.55.003 - Intellectual Disability, Australia, 2012

<sup>3</sup> Meltzer, A., Bates, S., Robinson, S., Kayess, R. Fisher, K.R. and Katz, I. (2016). What do people with intellectual disability think about their jobs and the support they receive at work? A comparative study of three employment support models: Final report (SPRC Report 16/16). Sydney: Social Policy Research Centre, UNSW Australia.

Down Syndrome Australia welcomes this review as anecdotal feedback from our community suggests that performance of the Disability Employment Services is variable at best. Feedback from people with Down syndrome and their families have indicated that the current approach to DES is not working for a number of reasons including:

1. There is no funding or support for additional employment once the benchmark minimum hours are reached which means that for some people if they are working 8 hours per week there is no additional support to achieve a position with more hours of work.
2. Staff often have a limited understanding of intellectual disability and do not have appropriate training to provide appropriate support
3. There is little or no support for people with an intellectual disability to establish a skills pathway and receive appropriate training to obtain meaningful mainstream employment
4. Clients are often not matched appropriately to employment (due to employers trying to meet targets) and as a result the employment is not sustainable.
5. There is need for specific tailored training and support for both the employer and employee, particularly when establishing employment. Down Syndrome Australia has developed resources which can be found here:

[http://www.downsyndrome.org.au/documents/resources/employment/Down\\_Syndrome\\_in\\_the\\_workplace\\_A5\\_Employers\\_accessible.pdf](http://www.downsyndrome.org.au/documents/resources/employment/Down_Syndrome_in_the_workplace_A5_Employers_accessible.pdf) and

[http://www.downsyndrome.org.au/documents/resources/employment/Down\\_Syndrome\\_in\\_the\\_workplace\\_A5\\_Employees\\_accessible.pdf](http://www.downsyndrome.org.au/documents/resources/employment/Down_Syndrome_in_the_workplace_A5_Employees_accessible.pdf)

Given these concerns, Down Syndrome Australia welcomes the review and the focus on improving choice and control for participants, engaging more employers to employ people with a disability and ensuring that providers support all people with disability equally. It is essential that the review consider how to achieve a higher level of sustainable and meaningful employment for people with intellectual disabilities.

We are concerned, however, that this review is limited in scope and does not take the holistic approach which is required to improving employment opportunities for people with a disability including examining interface issues such as access to inclusive education, interface with other support agencies and reforms, skills training and broader issues around stigma and understanding of intellectual disabilities. For example, there is currently a significant interface issue between DES and supported employment in the Australian Disability Enterprise organisations, with difficult transitions for individuals wanting to move from supported to open employment. In addition, there is an argument to be made that Disability Employment Services should be working closely with schools to support post-school transition into employment for people with a disability. Unfortunately, this review does not provide an opportunity to explore these interface issues as it specifically indicates a range of services/supports which are out of scope for this review. Changes to the Employment Services should not happen in isolation and consideration needs to be given to how the DES interfaces with other disability supports including NDIS.

## Responses to Specific Discussion Points

Please find below specific responses to selected discussion points raised in the DSS Discussion paper.

### **Discussion Point 1: More Choice for Participants**

1. What, if any, restrictions should there be (for example, region or distance) on participants choosing to attend a provider?
2. How often should participants be allowed to voluntarily transfer or switch providers?
3. What should be the basis of referral by Centrelink for participants who do not choose a provider?

Down Syndrome Australia believes that people with a disability should have free choice about the provider that they use, regardless of any geographical distances. This will enable people to access a provider who can best meet their needs and may have specialist services available for a specific disability (e.g. intellectual disabilities) or focus on particular employment types. With the use of the internet and other forms of communication, it is possible for people to access services appropriately regardless of location. Some people may prefer non-specialist providers, but the key is ensuring freedom of choice.

Participants should be supported to switch providers as required without being required to justify their position. The limits proposed in the Discussion paper, with three transfers in the first year and two in subsequent years without any documentation for rationale is appropriate.

For participants who do not choose a provider, it would be more appropriate to ensure that the individuals are supported to make a choice or at least document their preferences rather than putting in place an automated system to match to a provider based on a specific set of criteria.

Consideration should also be given to expanding the choice of providers to outside of the DES when considered appropriate. For example, utilising DES funding to access a professional recruitment or external job training/support agency.

### **Discussion Point 2: Provider/Participant Contacts**

1. Should face-to-face requirements remain as part of the DES service delivery?
2. How often should participants and providers be required to meet, either face-to-face or by other means?

Face to face meetings should be available to all participants but should not be a requirement. It is essential that the choice of method of communication is driven by the person with the disability rather than the requirements of the service provider. Recent experience with the NDIS suggests that when face to face communication is no longer the default, often people are not aware that they can still have access to this form of communication. It is critical that there is flexibility and choice but that this is reflected in true choice by people with the disability and not used as a mechanism for the provider to save costs. Often people with intellectual disability find face to face meetings to be more useful and supportive.

### **Discussion Point 3: Job Plans**

1. Should Job Plans have minimum requirements beyond what is necessary for mutual obligation requirements? Or should this be determined between each participant and their provider?
2. How can we ensure that participants are actively involved in the development of their Job Plans, or will the ability of participants to change providers if unsatisfied be sufficient?
3. How should providers be held accountable to ensure activities in the Job Plan are undertaken and supports are delivered? Will the ability of participants to change providers if unsatisfied be sufficient?

Job plans should be developed in collaboration with the person with a disability and should set out clearly the goals, targets, and responsibilities for all parties. It is essential that the participant have a good understanding of the plan and that it is co-designed. In some cases, the person with a disability may require a support person to assist them in this process, and this should be accommodated. In addition, any reasonable accommodation should be made including providing the Job Plan in an Easy-read version for people with an intellectual disability. Providers should be required to assess the participant's satisfaction with the planning process and the outcome. Participants should be able to change providers if unsatisfied with this process. In addition, plans should be portable and should be shared with subsequent providers if a participant is happy with their plan and chooses to change providers for another reason.

### **Discussion Point 4: Better Information for Participants**

1. What information should be available to participants, providers and employers?
2. Should there be mechanisms to ensure no false or misleading claims are made against DES providers?
3. Should the Department facilitate access to information on accessible and user friendly platforms, or should this be purely market led (with providers offering such information on platforms of their own choosing)?

Participants should have access to appropriate information that will enable them to make fully informed decisions about providers, services and supports. For people with an intellectual disability it is essential that this is provided in an appropriate Easy-Read format and supported decision making is facilitated. Information will be needed on the role of the DES, what services they will provide, what options there are for choosing a provider etc. It is essential to tailor the information to not overwhelm participants at entry, but also provide sufficient information to support informed choice.

The Department should facilitate accessible information to ensure that people with a disability including those with intellectual disability can make informed choices and have an understanding of the role of the DES.

There is no need for further mechanisms regarding false or misleading claims as DES providers are protected under current legislation and any further mechanisms may appear punitive and restrict discussion of provider performance.

#### **Discussion Point 5: Participant Controlled Funding**

1. There is considerable literature and experience in participant controlled funding in personal care. Is there any evidence of the effectiveness of participant control of third party funding in employment services?
2. In such a model, how much funding, if any, should be quarantined for job seekers to use through an account, how should this funding be made available to participants, and how could there be simple clarity as to what costs are to be met from participant controlled funds versus provider controlled funds?
3. What principles should guide the appropriate expenditure of any individualised funding?
4. What restrictions should apply to the use of the funds by participants?
5. How can participants who are unwilling or unable to use individualised funding be supported during the decision making process?
6. What restrictions should apply to the expenditure of the funds on services from a participant's provider or an associated organisation?

One of the areas of concerns raised by our members is that the DES do not provide support for long term career/employment skill development. The priority of the DES is to move people into employment as quickly as possible due to trying to meet their targets. Currently there are no incentives in place to support training and skill development focused on longer term benefits and goals. Providing participants with control over funding is one way to address some of these concerns.

In the view of Down Syndrome Australia, at a minimum there should be transparency about the funding held by the DES and the participant should be involved in decisions about the best use of this funding. The question of who administers the funding needs further consideration, but there could be multiple models as there is with the NDIS. There should be a requirement to link the spending with a clear goal related to future employment. As part of the development of the job plan, the participant should be supported to make supported decisions regarding the use of the funding. If an individual wishes to use funding for a particular support or training and this is refused by the DES there should be avenues for mediation on the issue.

#### **Conclusion**

The review and changes outlined to the DES provide an opportunity to reconsider the approach to employment support for disability in Australia. It is critical that supports are put in place to enable long term, sustainable and meaningful employment for people with a disability. The Discussion paper provides a number of proposals which have the potential to lead to greater support, choice and control for people with a disability. As outlined in the paper, there are a range of systemic issues which contribute to low-levels of employment for people with disability, and this needs to be addressed as part of a more comprehensive review and strategy for disability and employment in Australia.