Leave No One Behind

Advocacy Platform

Down Syndrome
Australia

About Down Syndrome Australia

Down Syndrome Australia (DSA) 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 document is to set out key issues which are important to people with Down syndrome and their families. We are asking for all of the political parties to consider these key *calls to action* ahead of the next federal election and to address them in their election commitments.

Overview

Down syndrome is a genetic condition in which the person has an extra copy of chromosome 21 in some or all of their cells. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. It is estimated that 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.[1]

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 general childcare settings, pre-schools, primary and high schools alongside children without disability. Some adults with Down syndrome are involved in their communities 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.[2]

Despite this progress, people with Down syndrome still face stigma and discrimination. DSA is advocating to government for changes to key systemic issues which have significant impacts on people with Down syndrome and their families. Below are the key issues and recommendations from DSA. More detailed information about each of these action items is provided further in the document.

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[1] DSA, *Research and Statistics*, 2[website],2013, **https://www.downsyndrome.org.au/research_and_statistics.html** (accessed 31 January 2019).

[2] J. Torr et al., 'Aging in Down syndrome: Morbidity and mortality', *Journal of Policy and Practice in Intellectual Disabilities,* vol. 7, no. 1, 2010, pp. 70-81.

Call to action 1: Prenatal screening

Government must ensure that families have the information they need to make informed decisions about prenatal screening for chromosomal conditions. It is unethical to have a screening program in place without access to good information and support.

Call to action 2: NDIS

Government must ensure that people with Down syndrome get the services and supports they need through NDIS, including through automatic eligibility.

Call to action 3: Health inequalities

Government to invest and prioritise funding to address the poorer health outcomes for people with intellectual disability in the Australian community through an investment in primary care programs and university training. This call to action is based on a campaign being led by Inclusion Australia and the New South Wales Council for Intellectual Disability (NSWCID).

Call to action 4: Education

Government must set a goal of ensuring a universally accessible and fully inclusive education system and move expeditiously and effectively towards that goal by adopting clear targets and timetables.

Call to action 5: Employment

Government must commit to improving access to open employment for people with an intellectual disability. This includes addressing barriers, supporting specialised Disability Employment Service (DES) providers, ensuring appropriate supports are provided under NDIS, and developing better support for transition from school to open employment.

Call to action 6: Migration

Government must remove the discrimination in the migration regulations based on whether a person has a disability.

Call to action 7: Sustainable funding for disability-specific peak organisations

Government must commit to ongoing, recurrent funding for disability-specific peaks to ensure the important role they provide in advocacy and informing government is sustainable.

Call to action 8: Affordable housing

Government must commit to increasing the supply of affordable housing and ensure housing is available in areas with good access to public transport to enable access to support services and employment.

Call to action: Prenatal screening

Government must ensure that families have the information they need to make informed decisions about prenatal screening for chromosomal conditions.

What is the issue?

Due to changes in medical technology, it is now possible to screen for chromosomal conditions earlier in pregnancy. Research indicates that, currently, many families are not fully informed prior to screening, and are not given balanced information about Down syndrome after screening occurs. While the Department of Health has produced **guidelines on prenatal screening**, there is no coordinated approach to their implementation. Families accessing prenatal screening are making decisions about whether to continue their pregnancy without the assurance of consistent, accurate and balanced information. An ethical screening program must include appropriate information and support.

What do we want to achieve?

That families who are contemplating prenatal screening/testing understand the implications of the screening they are considering including the accuracy of the results. That balanced information about Down syndrome, including opportunities to connect with other families, is available to families at all stages of the screening process.

How can this be done?

DSA recommends that the government take steps to ensure that parents are able to make informed choices about prenatal tests. This includes access to balanced information, support and opportunities to connect with other families. The existing guidelines provide a solid starting point. The focus must now be on implementation. This should include:

1. National training program
Funding for a national training program and resources for relevant health professionals to ensure that they are providing the appropriate information and support. This direct training will allow the guidelines to be adhered to.

2. Access to counselling
Following a screening result of a high likelihood or diagnosis of Down syndrome, all families should have access to counselling by appropriate health professionals (e.g. genetic counsellors) and be offered support to connect to other families through Down syndrome organisations.

3. Public awareness campaign
Representative organisations and people with Down syndrome would welcome a collaboration with government to develop a public awareness campaign which tackles the stigma associated with intellectual disability and raise public awareness about Down syndrome and other chromosomal disorders

For more information, read the **DSA position on Prenatal Screening**.

Call to action: NDIS

Government must ensure the NDIS is working for all participants including people with Down syndrome.

What is the issue?

The NDIS represents a fundamental shift in how people with a disability access the services and supports that they need. For most people with Down syndrome the roll-out of the NDIS has led to better access to services and supports. Unfortunately, this is not the case for everyone.

In 2018, DSA conducted a survey on NDIS experiences. This survey revealed that there are significant issues regarding access to the Scheme, planning experiences, and plan implementation. (The full survey outcomes can be downloaded here: **https://www.downsyndrome.org.au/documents/NDIS_Survey_2018.pdf.**)

Key issues included:

- Families spending significant amounts of money to get specialist reports to prove eligibility for NDIS.
- NDIS representatives in the planning meeting having a poor understanding of Down syndrome.
- Incorrect information about what services could be included or being told they need to use segregated services.
- Difficulty getting access to services needed to implement the plan.

What do we want to achieve?

DSA supports Every Australian Counts, Make it Work Campaign. We need to ensure that the NDIS is working for everyone who needs it. For people with Down syndrome there is a need to remove barriers to access, improve the planning experience and ensure access to services.

How can this be done?

DSA recommends that the government take steps to ensure that the NDIS is working for people with Down syndrome. This includes:

1. Moving Down syndrome from List B to List A to ensure automatic eligibility. Currently there is clear evidence that the vast majority of people with Down syndrome meet NDIS eligibility requirements. The current approach to access is creating unnecessary costs for the NDIA as well as creating unneeded stress and costs for families.
2. Continued work to improve the planning experience and the skills and training of planners. DSA has been pleased to be involved in work with the NDIA to develop materials to support planner training. The impact of these changes should be evaluated and further support provided as required.
3. Families need support to assist them in plan implementation and assist them to connect with appropriate services.

Call to action: Health inequalities

Government to invest in and prioritise funding to address the poorer health outcomes for people with intellectual disability in the Australian community. DSA is supporting the Inclusion Australia and NSWCID campaign on health inequalities.

What is the issue?

General practitioners and nurses have minimal training in intellectual disability health care. An average of 2.6 hours of an entire medical degree is dedicated to intellectual disability while in the majority of nursing degrees there is no content specific to intellectual disability.

There are stark and costly health inequalities for the 450,000 people with an intellectual disability in Australia. Research shows that, compared to the general population, people with intellectual disability experience:

- over twice the rate of avoidable deaths
- twice the rate of emergency department and hospital admissions
- twice the cost of hospital admissions
- higher rates of physical and mental health conditions
- lower rates of preventative healthcare.

We recognise the research-validated, annual Medicare health assessments for people with intellectual disability, but the take-up is low. Health professionals also face challenges including; communicating with people with intellectual disability, distinguishing health problems from the disability, and diagnosing complex health conditions.

What do we want to achieve?

Increase the capacity of health professionals to understand and work with people with an intellectual disability to improve health outcomes.

How can this be done?

Alongside Inclusion Australia, NSWCID and a consortium of other organisations, we advocate for a commitment to the following three proposals in the 2019 budget or, failing that, the Federal election:

1. A specific, funded program to enhance the capacity of GPs and other primary health care services to respond to the needs of people with intellectual disability.
2. Development, piloting and evaluation of curriculum enhancements in university medical and nursing schools.
3. A national inquiry into the health of people with intellectual disability.

More information can be found at:
https://www.inclusionaustralia.org.au/

Call to action: Education

Government must work towards a universally accessible and fully inclusive education system and move expeditiously and effectively towards that goal by adopting clear targets and timetables.

What is the issue?

The Australian education system is not universally accessible and inclusive, and many children with Down syndrome and intellectual disability continue to face barriers that deny them this fundamental right. Recent research indicates that less than 50% of students with Down syndrome are enrolled in mainstream education. There is clear evidence that the delivery of education to students with disability in general education settings leads to better academic and social outcomes and provides a pathway to living, working and fully participating in the community.[3] Provision of inclusive education is one part of addressing barriers to inclusion in the broader community.

What do we want to achieve?

That all children are welcomed as equal members of an educational community and their full participation is supported. DSA's position is that access to inclusive education is a fundamental human right for all Australian children, with or without disability. This right is outlined in The UN Convention on the Rights of Persons with Disabilities (UNCRPD) (of which Australia is a signatory) and reflected in Australian law.

How can this be done?

Australian and state governments commit to transitioning from a dual system of special schools and mainstream schools to a single universally accessible and inclusive education system. This would require:

1. Legal and policy reform

A consistent definition of inclusive education, reflecting the UNCRPD and General Comment No. 4, should be adopted by all governments and the right to inclusive education should be more clearly enshrined in legislation.

2. Support for teachers

Including a focus on inclusive classrooms during teacher training and access to ongoing professional learning as required.

3. Adjusted curriculum

Adjustments of the year level curriculum should be available for all students and students assessed on the adjusted curriculum.

4. Complaints process

All those involved in the education of learners with disability need an easily accessible system of reporting. The current option of complaints to the Australian Human Rights Commissioner should remain as an avenue when other options have been exhausted.

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[3] Alana Institute, ***A summary of inclusive education***, [website], 2016, https://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf, (accessed 31 January 2019).

Call to action: Education cont.

5. Support for parents
Organisations need to be funded to provide parents with the support they need to access inclusive education including information about legal rights and the benefits of inclusive education.

6. Funding and resources
Schools must be appropriately funded to support access to inclusive education. Resources should be transitioned from specialist schools to the general education setting, with specialist teachers available to provide expert advice to general classroom teachers. Expert bodies, such as DSA, should be funded to provide professional development support to teaching teams.

For more information, read the **DSA position on Education**.

Call to action: Employment

Government to improve access to open employment for people with intellectual disability.

What is the issue?

People with Down syndrome want to work for the same reasons as everyone else – so that they can be independent, contribute to society, earn their own money, learn new skills, meet new people, and feel valued. There is strong evidence from both Australia and internationally that people with an intellectual disability can work within open employment and that open employment leads to better outcomes than segregated employment (workplaces specifically for people with disability). However, only 11% of people with intellectual disability aged over 15 who receive disability services, work in open mainstream employment.

What do we want to achieve?

DSA 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. By improving pathways to open employment and providing the right supports and information, people with intellectual disabilities will have increasing opportunities to work in the community alongside their peers.

How can this be done?

1. 'Open employment first'.
NDIS should help people build the skills they need to find and keep work in open employment. They should only give people money to support them to work in an Australia Disability Enterprise (ADE) when other choices such as mainstream employment, further education and training, and volunteering have been carefully considered first.

2. Better support to move from school to open employment.
Schools often place students with intellectual disability in ADEs for work experience. This means they don't get the chance to try out different opportunities or develop their skills. Students with intellectual disability must get the same chance as other students to do work experience in open employment.

3. Make it easier to use DES providers.
DES providers help people with disability to find work in open employment. But only 4% of people who use DES supports have an intellectual disability. One of the main reasons for this is that people with disability have to do an assessment to see if they can work at least eight hours a week. If the assessment says the person can't do eight hours, then they can't get DES support for open employment.

Call to action: Employment cont.

We know that people with intellectual disability can do much better at work when they get training and support in the workplace, but the job assessments are done before people get the chance to show this. DSA recommends that if a person wants to work in open employment, and wants to learn the skills they need, they should be able to get DES support without this assessment requirement.

4. Better support for Specialist DES providers.
DES providers should get more money from government to help people who need support over a longer time to do their job. There needs to be more DES providers that specialise in supporting people with intellectual disability.

5. Better further education for people with intellectual disability.
There are a few places in Australia that have education programs for people with intellectual disability when they have left school. But there aren't many. There needs to be greater investment by government in post-school education opportunities for people with intellectual disability.

For more information, read the **DSA position on Employment**.

Call to action: Migration[4]

Government to remove the discrimination in the migration regulations based on whether a person has a disability.

What is the issue?

Australia's migration health requirements are intended to protect public health, protect the right of Australian citizens and existing permanent residents to access scarce health resources, and limit the impact of migration on health and disability support services. While recognising the importance of these criteria, DSA believes that the current health requirements discriminate against people with disabilities, which is unacceptable.

The Australian government currently places restrictions on visa applicants and their family members who have a disability or a health condition which the government deems likely to be a 'significant cost' to the Australian community. DSA is deeply concerned by these restrictions and believes they are unwarranted.

The 2010 Joint Committee Inquiry into the Migration Treatment of Disability (Enabling Australia inquiry) highlighted many discriminatory provisions and made significant recommendations into migration practices in the area of disability. Despite the promises made by the government in its 2012 Response to the Enabling Australia Inquiry, many of these provisions remain in place and the majority of the recommendations which the government undertook to implement as a result of that inquiry have not been implemented. DSA believes it is time to revisit that inquiry and assess what remains to be done.

Australia has laws which prevent discriminatory treatment of people with disabilities, and is a party to international law with the same aim. Australia's *Disability Discrimination Act 1992* (DDA) aims to protect individuals from unfair treatment on the grounds of their disability. Yet this protection does not extend to those applying for a visa to enter Australia, on either a temporary or permanent basis, since the *Migration Act 1958* is exempt from the provisions of the DDA. Further, while Australia is a signatory to the UNCRPD, the Australian government has introduced an exemption to the UNCRPD which permits Australia to ignore the UNCRPD with regard to migration.

Other nations with a comparable social security system to Australia, such as Canada, have attempted to resolve the issue of discrimination in migration. DSA believes it is past time Australia moved in a similar direction.

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[4] DSA acknowledges Dr Jan Gothard, a Registered Migration Agent (MARN 1569102) and DSA's migration consultant, for her work on this section of our platform.

Call to action: Migration cont.

What do we want to achieve?

DSA believes Australia's migration system should be in line with existing national and international law that does not discriminate against people with disabilities. Australia's migration system should recognise the benefits people with disabilities can bring to the community and not assume that people with disabilities are purely a burden.

How can this be done?

DSA calls on the Australian government to:

1. **Review the recommendations of the 2010 Enabling Australia inquiry and the 2012 Response**, and to make good on promises and recommendations not yet met
2. **Amend the DDA to remove the exemption of the Migration Act 1958 from its scope**
3. **Adhere fully to all provisions of the UNCRPD**
4. **Look to what is happening overseas.** The government should examine the recent changes implemented by the Canadian government to their migration health and disability requirements with a view to establishing a new non-discriminatory Australian migration model for the future.

Call to action: Sustainable funding for disability-specific peak organisations

Government to commit to ongoing, recurrent funding for disability-specific peaks to ensure the important role they provide in advocacy and informing government is sustainable.

What is the issue?

Disability-specific peak organisations, such as DSA, are uniquely placed to bring together the range of views and experiences within our specific disability communities to provide coordinated strategic representation to the government. This includes being involved in the implementation of the NDIS, providing advice to the Department of Social Services and acting as a conduit for information to our members. However, the disability-specific peak organisations are currently receiving less than $30,000 each per year from government to do their core work. As a result, they are relying on project funding or ILC funding to support their activities. Organisations are unable to focus on their core activities and some are struggling to survive.

Our organisations have well developed experience and networks which will be lost without sustainable funding. As noted by a review of the disability peaks by Purple Orange: ‘Loss of the specialist peak organisations results not only in a loss of strategic advice and expertise to governments but also compromises the support available to people with disability. If the disability-specific peaks cease to exist, this valuable source of information and expertise will not only be lost to governments but lost to people with disability themselves.’[5]

What do we want to achieve?

Adequate funding of disability-specific peak organisations to ensure the provision of ongoing advice and information to government, and the representation of their membership bases.

How can this be done?

1. Recurrent annual funding of $220,000 per organisation be provided to the 10 Disability Australia Consortium Peaks (DACP) organisations by government.

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[5] The survival of people-with-disability organisations, Purple Orange & Julia Farr 2016.

Call to action: Affordable housing

Government to commit to increasing the supply of affordable housing and ensure housing is available in areas with good access to public transport to facilitate access to support services and employment.

What is the issue?

There is a well-established link between appropriate housing and health, workforce participation, and community involvement. People with a disability often experience considerable disadvantage in the housing market and are particularly vulnerable to the negative effects of residing in inappropriate accommodation. In 2018, less than 1% of Australian rental properties were affordable and appropriate for people with disability, with just 485 of 67,365 properties affordable for people on the Disability Support Pension[6]. There is also evidence indicating that people with disability are more likely to live in public or social housing, less likely to own their own home and experience housing stress (defined as paying more than 30% of income on housing costs).

What do we want to achieve?

DSA believes access to affordable and safe housing is a basic human right for all people living with a disability. This right is outlined in the UNCRPD (Article 19), to which Australia is signatory, which states that people should 'have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

How can this be done?

DSA recommends:

1. The government increase the rates of the Disability Support Pension and their indexation to keep pace with living standards and housing cost and reduce housing stress for people with disabilities.
2. The government should undertake a review of Commonwealth Rent Assistance, its eligibility conditions and indexation rates (to ensure it adequately changes with the Consumer Price Index and changes in the rental market), and its effectiveness in protecting against the increasing costs of rent.
3. The government increase the supply of affordable housing, including public, community, and other low-income rental properties and ensure that new housing stock reflects the diverse needs of Australia's population including those living with a disability.
4. The government should increase the supply of housing in locations with good access to public transport in order to facilitate access to both services and employment.

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[6] Anglicare Australia, *Rental Affordability Snapshot 2018*, [website], 2018, **http://www.anglicare.asn.au/docs/default-source/default-document-library/final---rental-affordability-snapshotb811d9309d6962baacc1ff0000899bca.pdf?sfvrsn=4**, (accessed 31 January 2019).

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