



Submission to 2020 Review- Disability Standards for Education

September 2020

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 the Down Syndrome Federation. The Down Syndrome Federation works together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome. The Federation is made up of Down Syndrome Australia and the State and Territory Down syndrome organisations. 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 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.¹

For more information contact:

Dr Ellen Skladzien
Chief Executive Officer
Down Syndrome Australia
Email: Ellen.skladzien@downsyndrome.org.au
Website: www.downsyndrome.org.au

¹ Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/>

Submission to Disability Standards for Education

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the Department of Education, Skills and Employment on the 2020 Review of the Disability Standards for Education.

As outlined by the discussion paper, the Disability Standards for Education 2005 (**Standards**) seek to ensure that students with a disability can access and participate in education on the same basis as students without a disability. The Standards set out the rights of students with a disability, the legal obligations of education providers, and examples of what can be done to meet the requirements of each part of the Standards.

Many of the concerns raised in the 2015 review of the Standards remain relevant² including:

- lack of awareness of the Standards amongst people with a disability and their families;
- the lack of clarity around the meaning and implementation of “reasonable adjustment” obligations, “unjustifiable hardship”, and “on the same basis”;
- reliance on a complaints-based enforcement mechanism; and
- large numbers of examples of school-based practices that breach the Standards, which illustrate the need for change in how the Standards are implemented.

Down Syndrome Australia receives regular reports from families about difficult interactions and experiences within schools. Students with Down syndrome are at times turned away from mainstream schools, or do not receive appropriate adjustments and supports once enrolled. At times teachers may not be appropriately skilled or supported to meet the requirement to provide appropriate adjustments. In some cases, research does not exist to determine evidence-based practices in the provision of reasonable adjustments, such as for assessment. Communication with families that is based on mutual respect and negotiation around reasonable adjustments does not always occur. Sometimes schools seemingly meet their legal requirement to consult families, but in practice this can be about informing them about decisions already made rather than genuinely consulting with them. There is a clear need to make improvements to the Standards to ensure that all students with disability have access to mainstream education and can get the adjustments and supports that they require.

Inclusive Education

Although the Discussion Paper for this consultation suggests that discussions about the best way to provide education to students with a disability and issues around inclusive education are outside the scope of this review, we believe that these issues are central to the review and cannot be separated from the operation of the Disability Discrimination Act 1992 (DDA) and the Disability Standards.

² Australian Government. Department of Education Skills and Employment (2015). Final Report of the 2015 Review of the Disability Standards for Education 2005.

Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and therefore has agreed, under international law, to its domestic implementation.

Article 5 of the UNCRPD imposes an obligation on State Parties to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds” and to “take all appropriate steps to ensure that reasonable accommodation is provided.”

The UNCRPD further includes Article 24: A Right to Inclusive Education which guarantees students a right to education within the general (‘mainstream’) education with appropriate supports “consistent with the goal of full inclusion”.

Article 24.1 of the CRPD states:

“State Parties recognise the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels”

Article 24.2 further states:

“In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability ...;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual’s requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

The DDA purports to implement Australia’s international law obligations under the UNCRPD. The Disability Standards are the subordinate legislation under the DDA which focuses on education. The DDA and the Standards do not provide for the right to inclusive education or any process for creating systemic change to promote inclusive education within Australia. This is inconsistent with our obligations under the UNCRPD and needs to be corrected in either the DDA or the Standards.

Down Syndrome Australia adopts the position, consistently with international human rights law applicable to Australia, that access to inclusive education is a fundamental human right for all Australian children. Down Syndrome Australia has endorsed the **ACIE Roadmap for Inclusive Education** which calls for a national strategy to implement an inclusive education system and includes the need for a reform of the DDA and review of the Standards to ensure that they are consistent with the UNCRPD.

There is overwhelming evidence that inclusive education leads to better academic and social outcomes for both students with and without a disability. The most recent comprehensive review of the research was undertaken by the Alana Institute and released in 2016. The research shows that all students benefit from an inclusive education setting. The researchers found ‘clear and consistent evidence that inclusive educational settings can confer substantial short and long-term benefits for students with and without disabilities’.³ There is also evidence that attending segregated schools minimises opportunities for social inclusion within the education setting but also has a long-term impact on social inclusion.⁴ Many students who attend segregated schools go on to work in segregated workplaces and have fewer opportunities to live independently.

DSA argues that the education system needs to be reformed to ensure that it is able to provide a high-quality inclusive education to every student, that respects their individual characteristics and meets their educational needs. It is the view of DSA that families should not be responsible for fighting for effective inclusive practice. Rather, it should be the responsibility of systems to meet their obligations under the Disability Discrimination Act 1992 and the Disability Standards for Education. The Standards should be revised to ensure that they clearly protect and promote the rights of students to access inclusive education. In addition, the Australian government should consider more comprehensive legal reform to recognise and provide for the fundamental human right of students with disability to inclusive education on the basis of equality and non-discrimination, and to drive the system-wide implementation of inclusive education.

There is a need for a shift from the Standards being utilised as a complaints-based enforcement mechanism to one in which the Standards support and promote access to inclusive education. It should be noted that in the 2015 review, Recommendation 10 suggested the Australian Government explore the feasibility of a nationally consistent monitoring and accreditation model to strengthen pro-active compliance with the Standards.⁵ This type of pro-active approach coupled with Standards which specifically identify the rights of students to access inclusive education would support Australia to meet its obligations under the UNCRPD and importantly lead to better outcomes for students with a disability.

Barriers to Participation for Students with Intellectual Disabilities

Students with intellectual disability face a range of barriers to participation in mainstream education. Some of the barriers for students with Down syndrome which have been raised by young people with Down syndrome and their family members include:

- ‘gatekeeping’ by schools in which the principal or teachers indicate that they do not have the skills or resources to support the student

³ Alana Institute (2016). A summary of inclusive education. Retrieved from http://alana.org.br/wpcontent/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf

⁴ https://www.european-agency.org/sites/default/files/Evidence%20%E2%80%93%20A%20Review%20of%20the%20Literature_0.pdf

⁵ <https://docs.education.gov.au/system/files/doc/other/final-report-2015-dse-review.pdf>

- teachers who claimed to have had little training about disabilities, and who may lack the information/support to make appropriate adjustments to the curriculum for children with intellectual disabilities
- lack of access to appropriate supports (teacher aids/support workers in class)
- delegation of responsibility for the student's education to the teacher aide
- concerns about safety or health issues
- exclusion from school activities (camps, drama, music, sport) or expectation of parental involvement in order for the student to attend
- families told their child can only attend on certain days or times
- applications being rejected from private schools
- families being asked to pay additional school fees to cover teacher aide provision prior to enrolment in private schools
- lack of meaningful collaboration on Individual Education Plans
- fear of retribution if concerns are raised by parents
- lack of access to post-school training opportunities.

A 2017 Down Syndrome Australia survey found that a third of families reported that their child with Down syndrome had been excluded from education or related activities because of their disability. This included exclusion from sports, camps, excursions, extracurricular activities.

These results are consistent with other Australian data. For example, Children and Young People Disability Australia (CYDA) has repeatedly shown through their annual national Surveys on education that students with disability are excluded from education. In their 2019 survey, they found that 40% of students with a disability were excluded from events or activities at school in the last year. They also found that 12.5% of students with disability had been refused enrolment.

Enrolment

A number of families told us about difficulties in enrolling in particular schools because of a child having a disability. Below are a few of the many examples we received from families talking about their experiences.

- *I applied for my son to be at a private primary school and our application was rejected. Reason given was their focus was on academic achievements.*
- *When looking around for a school we have had coordinators/principals suggest that their school might not be the ideal setting for our son - code for send him anywhere but here.*
- *I was told there is a special school that would be a better place for him. When I told the principal that I wanted him to attend a regular school with his sister, she said that their school would not be able to provide the supports he needed.*

- *The principal at the primary school I had chosen for T tried very hard to turn us away even arranging for a psychologist to talk me out of sending T to her school. T occasionally needed an ambulance during school hours. This principal said that this was very upsetting for the other students. No mention of T's welfare.*

Participation

We were also told by families about the difficulties students had in participating in the school on an equal basis. This often occurred in relation to camps, or extracurricular activities. Below are just a few of the quotes we received from families talking about the difficulties in participation.

- *The primary school she had her name down for a school camp from the beginning of the year, then at the last moment (2 days before camp) they told me she couldn't go because there was no one to support her. I was fuming ... called DS office and got the number of the antidiscrimination ombudsman, and she went on camp ... but it should not have happened like this.*
- *At mainstream school, my daughter was unable to take part in activities like camp due to lack of support to help her.*
- *My teenager has been excluded from school excursions as they are aimed at mainstream children ... activities at camps not scaled down enough and also issues with food and not eating the one meal offered at mealtimes. I have offered to provide a meal, heat only and was told that cannot be done.*
- *We are often asked to consider alternative options at school. Sometimes he is not taken to the oval at school or to specific classes because he has to walk further or negotiate stairs, etc. They assume he will 'get tired'. We have been asked to pick him up early and start him later because he is slower on the stairs (they have put him in a class up 2 flights of stairs). When he first started school we were asked to consider part time schooling. We refused to start him any less than the other reception students and he has managed it fine. I often find that people just assume he can't do something because he has DS before they even try. I just want them to try the 'normal' way first and if that doesn't work, then look at Plan B. They tend to go straight to Plan B all the time.*
- *My child has been repeatedly excluded from some school excursions without asking us. For example, sometimes we find out there is a drama excursion or play try outs on the next day from fellow parents but no note sent to us even though we have requested information comes to us as well . We can't always rely on our son to tell us or bring the note home.*

Curriculum

Families also told us about schools not making appropriate adjustments to the curriculum for the student with a disability.

- *They are sending my teenage daughter home with worksheets about the Hungry Caterpillar story. This obviously does not interest her. How can they expect her to learn if they treat her like a pre-schooler?*
- *The school does not seem to understand how to support S's learning. She is very interested in numbers and wants to learn maths but they keep giving her work that is too easy. She wants to be challenged but she does not have opportunities.*

- *My daughter is constantly shadowed by a SSO. They aren't giving her a chance to be independent or try to learn on her own.*
- *When I complained that she was not getting the support she needed to learn in the classroom, the principal suggested that I might want to look at other options or maybe a special school.*

Families have also noted that in some cases there is little accountability for the outcomes for students with intellectual disability. Often students are encouraged not to participate in NAPLAN and their progress on literacy and maths is not tracked. If students reach secondary school and have not yet learned to read, appropriate adjustments are not always made for students.

These stories from families illustrate just some of the challenges facing students with disabilities. The findings from the DSA survey suggest that the Disability Standards for Education are not effective in ensuring that students with a disability can access and participate in education on the same basis as students without a disability. In many cases, students are being enrolled in segregated learning environments because mainstream schools are unwilling to provide reasonable adjustments for that child, despite the requirement under the Disability Standards. It is unclear as to whether schools are unaware of their obligations under law, uncertain as to how to interpret the Standards or if they are aware of the difficulty in enforcing the Standards and therefore, willing to take the risk in not providing required adjustments.

Reasonable Adjustment/Unjustifiable Hardship

The Standards are problematic in their definition of 'reasonable adjustment' and 'unjustifiable hardship'. The use of this terminology is not consistent with the equivalent concept defined by the CRPD⁶. These terms are loosely defined in order to provide flexibility. This means that schools/educators can interpret these terms subjectively and this can make it even more difficult for families to be successful in any complaints lodged about adherence to the Standards. The lack of clarity around these definitions can make it difficult for parents to question or challenge a decision by the school. The school can say that they are complying with the Standards but that the adjustment in question is not considered reasonable or will lead to an unjustifiable hardship.

Reasonable adjustments are defined as "achieves this purpose [to assist a student to participate in education on the same basis as other students] while taking into account the student's learning needs and balancing the interests of all parties affected, including those of the student with disability, the education provider, staff and other students." This definition clearly leaves room for schools to argue that the requested adjustments are not 'reasonable' due to impacts on teachers or other students and seemingly places on the same footing the fundamental human rights of students with disability to education and other competing 'interests'. This approach is not appropriate or consistent with the UNCRPD. Schools utilise this clause to justify gatekeeping and not providing accommodation for students. For example, a student with high behaviour support needs may be rejected from enrolment because the adjustments required might have an impact on other students and teachers.

The Guidance Notes of the Standards indicate "If in a particular situation the school could show that a student would be better off in another available school which had the adjustments required by the student,

⁶ <https://www.cyda.org.au/resources/details/65/inquiry-into-free-and-equal-an-australian-conversation-on-human-rights>

then this would clearly be a factor in determining whether any significant adjustment at the school would be reasonable.”⁷ Again schools can use the option of a segregated learning environment to justify not providing adjustments for a student, as they could potentially receive those adjustments in another school environment. This is not consistent with a human rights approach of supporting all students to access inclusive education.

The Standards do not require changes to be made if they impose ‘unjustifiable hardship’ on the education provider. Again, this provides another opportunity for schools to argue that the adjustments required by a student with a disability cannot be met.

In assessing the reasonableness of an adjustment, an education provider can consider inherent or essential aspects of programs. Guidance notes of Section 3.5 (3) state, “In providing for students with disabilities, a provider may continue to ensure the integrity of its courses or programs and assessment requirements and processes, so that those on whom it confers an award can present themselves as having the appropriate knowledge, experience and expertise implicit in the holding of that particular award.” We acknowledge the importance of this statement but argue that there is danger in allowing any institution to claim that an aspect is inherent without a review mechanism. Furthermore, this provision needs to be clarified to ensure that what was intended to apply to university or vocational courses does not become misapplied to any teaching situation or level.

In our view, the DDA and the Standards should be amended to include a right to reasonable accommodations as a ‘default’ position as well as “non-rejection” provisions in relation to students with disability being turned away from ‘mainstream’ school.

Compliance/Complaints Process

The Disability Standards for Education rely on a complaints mechanism to drive compliance. There is no requirement for educators to demonstrate compliance with the Standards. As a result the Standards are not being utilised to create systemic change to the education system and to ensure inclusion, but instead are a tool to be used when appropriate adjustments are not made, and only by families with the social capital to do so.

Unfortunately, as noted in the 2015 review, awareness of the Standards amongst families is low and parents who are aware of the Standards are unsure about how to utilise the Standards to advocate for their child. Often parents are fearful of backlash or reprisal from schools if they use the Standards to advocate for their child. Some families are not comfortable having to advocate strongly for their child and choose the path they did not desire of withdrawing their child from the school or accepting a lack of accommodation for their child’s needs.

Depending on the State, the process for lodging concerns can be quite prolonged and lacking in a timely outcome for students. In most States the process of raising a concern about adherence to the Standards would include:

- Raise the issue with the teacher in question

⁷https://docs.education.gov.au/system/files/doc/other/disability_standards_for_education_2005_guidance_notes_0.pdf

- If not resolved raise the issue with the school leadership team (Principal)
- Raise the matter with the Department of Education/Training in that State
- Raise the complaint with the Human Rights Commission
- If not resolved by the Human Rights Commission - a process that can take around 2 years, the complainant can take the issue to the Federal Court.

Many families lack the time and energy to take the complaint to the Human Rights Commission. Even when they do take it to the Commission, some families have reported schools not being willing to fully participate in the conciliation process. Parents who choose to take the complaint to the courts face significant financial risks in addition to the stress and other impacts of taking legal action. The imbalance of power between families and education departments/large independent schools and education providers (who generally have much more access to the financial resources required to pursue matters through the courts) is problematic. Independent advocates can play an important role in supporting families through these matters, but inadequate funding for disability advocacy means that at times there is a waiting list or a lack of availability of advocacy services. In any event, individual advocacy services cannot overcome weak legal protections.

Children with intellectual disabilities find themselves in a system that lacks transparency and accountability where respect for their rights is largely dependent on the nature and beliefs of individuals. This lack of accountability is especially problematic given widespread societal biases and prejudice against people with intellectual disabilities⁸. There is a need to reform the complaints processes under the Disability Discrimination Act and the Disability Standards for Education to make them simpler, easier for individuals with intellectual disabilities and their families to access and ensure there is true accountability and consequence for those who knowingly breach the Standards.

As part of the implementation of the Standards there should be a clear mediation process for any disputes which can be made available to families before raising the issue further. As part of this, there should be a helpline or contact centre where both families and educators can talk about the issues confidentially and get ideas and supports. This would assist both educators and families to understand their rights and requirements under the Standards and avoid some of the failures that can arise.

Summary

There is strong evidence that many students with a disability struggle to get access to the supports they need within the education system. Many are turned away from mainstream education. The Standards are not achieving their aims and objectives to “ensure that students with disability are able to access and participate in education on the same basis as students without disability.”

The Standards and the DDA need to be replaced or supplemented with new laws, to ensure that Australia’s regulatory framework for education of students with disability fully aligns with the rights and concepts in the UNCPRD, including the approach to equality and non-discrimination applicable pursuant to the UNCPRD. The Standards should clearly outline the right of every student to be included in their local

⁸ Department of Health and Human Services Victoria State Government (2018) Survey of Community Attitudes toward People with Disability

school with adequate and intentional accommodations to ensure access on the same basis. Schools should not be allowed to deny enrolment or enforce reduced attendance.

Changes to the Standards should be done as part of broader education reform to achieve inclusive education in Australia and meet our obligations under the UNCRPD. The ACIE Roadmap⁹ provides a clear approach to achieving this outcome. The implementation of the Standards needs to include appropriate supports for both students and educators, such as a national helpline and a consistent approach to mediation when disputes arise.

⁹ <https://acie105204494.files.wordpress.com/2020/07/acie-roadmap-updated-30-july.pdf>