



Syndromes Without A Name (SWAN) Australia

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The Australian Government
Department of Education, Skills and Employment
GPO Box 9880
Canberra ACT 2601

25 September 2020

RE: 2020 Review - Disability Standards for Education 2005

To whom it may concern,

Thank you for the opportunity to write a submission with regards to the 2020 Review of the Disability Standards for Education 2005.

Background

Syndromes Without A Name (SWAN) Australia is the peak national peer support organisation that support and represent a large cohort of the approximately 400,000 Australian children that live with rare conditions. A 2013 study of 46 families living with rare conditions showed that 63% of respondents had some level of disability, of which 13% severe disability.(1) We represent people living with all possible forms of disability, physical, psychosocial, intellectual, autism, and more, and have consulted with a number of families across Australia – approved excerpts of their stories are contained within our submission with their permission.

We acknowledge the importance of the Disability Standards in Education (the Standards) and thank you for the opportunity to provide a submission as part of the review. COVID-19 has resulted in many parents having a renewed respect for education. For parents of children with disability it has also, in some cases, served to heighten awareness of the gaps for their children in support and participation opportunities.

Our submission is also informed by the United Nations Convention on the Rights of the Child, in particular:

- Article 3: All organisations concerned with children should work towards what is best for each child.
- Article 23: Children who have any kind of disability should receive special care and support so that they can live a full and independent life.
- Article 29: Education should develop each child's personality and talents to the full. It should encourage children to respect their parents, their cultures, and other cultures.

SWAN invited members to be involved in consultations to develop this submission. The responses have predominantly focussed on pre-school and primary school, but we also make comment on experience in high school and transition from high school.

We welcome the opportunity to discuss our submission further with you.

Kind regards

Heather Renton
Chief Executive Officer
Syndromes Without A Name (SWAN) Australia

Key Recommendations:

Our recommendations in relation to the Standard are as follows:

1. Collaborate and partner with parents to understand the education needs of children with disability and the response that will best support the child. Replace IQ tests with meaningful consultation with parents and health and disability support persons who work with the child to fully understand the needs of the child.
2. Review and adjust the guidelines for the application of the Standards to ensure that parents can do more than complain.
3. Develop an independent body for, and approach to, the review of complaints after initial discussions have occurred between the parent and school.
4. Parents should have the opportunity to enrol their child in the type of education institution they consider will best suit their child based on their unique and expert understanding of their child.
5. Transition programs for children with disability need to be improved, expanded and made more accessible to enhance their opportunities post schooling.

Familiarity with the Disability Standards in Education

As a national advocacy organisation SWAN Australia is familiar with the Standards and has regularly supported families in discussions with education institutions and provided advice on how they should expect the Standards to be applied. In our experience, the people we represent are often not aware of the Standards, how to utilise them and how they should be applied in education.

Experiences of people with disability in education and training

Enrolment

The respondents to our consultation all identified some issues with enrolling their child in school at kinder/preschool and primary school level.

One of the themes of responses in relation to enrolment were that it is 'luck of the draw' to get a mainstream school that will accept the enrolment and then provide the support that is required. Most had experience of the school suggesting another school, not wanting to enrol the child or saying they were not willing to make adjustments.

Another theme is that parents were advised the school did not have sufficient funding to provide support, that it is difficult and time-consuming to obtain and that if there is insufficient funding to support their child that they will not be able to attend school.

Parents report statements from schools such as:

"We don't take kids who could endanger the lives of other students."

"We even have trouble with the kid with Autism you'd be better looking at xx Special School."

Parents of a child who relies on access to an oxygen tank were told the kindergarten could not support their child, the parents self-funded support for that year to enable their child to attend 3-year old kinder with a support worker. When the same child was to be enrolled for primary school the local public primary school advised they could not accept the child prior to and the parents agreeing to a dual model of home school and mainstream school, prior to even considering applying for funding for support as they told the parents that their child would never get funding for a full time inclusion support worker.

Participation

The resistance to enrolment of children with disabilities in education was further reflected in the reports of the reluctance of schools to support participation and inclusion. Reported discussion with principals indicate a one-way consultation where parents are informed about what their mainstream school cannot do. Parents across Australia also indicated they were frequently not consulted about changes to routine or adjustments to programs that could accommodate their child or support their participation. One parent interview indicated: *"...we wanted to increase our child's capacity to attend school for a full day and the principal said they did not have the funding to support this."* They were not offered the opportunity to self-fund.

Parents report statements from teachers and principals such as:

"Children like X should not be at schools like this, they should be at special schools."

Events at schools we were advised of, included:

- A child with a dedicated aid went missing from the classroom and was not discovered until about 10 minutes later, there was no acknowledgement from the school that this was not appropriate.
- A child attended an independent early learning centre where they received two years support from a funded inclusion support worker. When it was time for the child to commence prep, the school told them that there was no government funding for an inclusion support worker and that the parents would need to fund their own if they wanted their child to attend the school along with a therapist team, as well as pay the independent school fees. The family paid for a full-time support worker as they did not know any different and took what the school said as correct information. The school then took ownership of managing the inclusion support worker, employing her direct with the parents funding. When the parents asked questions around their performance management, qualifications and expectations, the school refused to provide information and the family raised that they were not happy with the support worker. The family escalated their concerns and told the school they were breaching their child's human rights. The school admitted to receiving funding for their child but refused to disclose how much and refused to say how the money was used to support their child. The school is now providing a support worker one on one for the child but just prior to COVID-19, the family has been asked to collect their child early each day as the school does not have enough funding to support their child staying at school for the whole day.
- Another family turned to the Catholic System after disappointment with their local public primary school and received support of a full-time aid. However, when the child became too unwell to attend school, their child got treated like the 'sick kid' and there was no contingency with support to try and provide education support to try and catch up the child's learning. There was no contact from the school whilst the child was too unwell to attend. The school saw themselves more like a babysitting service. Something happened at school when he was in grade 2 so that comprised him emotionally, not sure what it was. The psychologist suggested to get them out of the environment as something was not right.
- A number of parents report there is limited to no communication from the school regarding their child's activities and daily and weekly care plans were ignored (Vic and Tas).

These stories highlight the lack of inclusivity and that schools do not appear to teach or demonstrate an approach that discourages discrimination. It is critically important for children and their carers to have the option to choose a school that suits their needs. Every student should have the opportunity to select the best learning environment for their child.

It should not have to be a case of 'school shopping' to find a school that will make the necessary adjustments. Access to participation in these schools and receive adequately funded supports, should not be limited by boundaries or IQ tests but should consider the range of issues the child and parents are living with. It is about offering parents' choice to best suit their child's needs.

Participation in social activities during recess and lunchtime are critical for teaching children life skills such as negotiation and compromise through interacting with other children. Children with a disability can often need additional support to interact with other children during break times and understand these interactions. The physical activity that occurs during this time is also important for health and wellbeing. Many parents reported that the support person in the classroom was frequently not available to support their child during these times and they missed this critical aspect of school participation.

Students with disability at mainstream schools also face challenges in participating in physical activity and health lessons. Their physical and intellectual abilities are not the same as their counterparts and there is limited adjustment. This is particularly evident in many primary schools where contract staff provide information on puberty sex education lessons where children with disabilities can take longer to assimilate the information.

Transition from school to the workforce or further education has been reported as being limited and inadequate. Children with disability do not have access to the range of supports that other students have to enable them to transition to education. These further limits their ability to access employment.

The use of IQ tests to decide on participation is not helpful to parents of students with disability. It creates stress for both the child and the parent and does not provide an accurate picture of the child's abilities and needs. An IQ of 70 does not mean the child can cope in a mainstream school.

Support

Whilst parents are generally aware of the opportunity for schools to support their child, they report a lack of ownership and autonomy in being able to access them such as inclusion support workers. Funding that enables the support in school is reliant on the school or kinder making an application for funding. Most parents who responded to our consultation reported they had to advocate strongly for the education institution to apply for funding and then had to regularly follow up to ensure the funding application was put in. Most also indicated the funding the school received appeared to be inadequate. Of significant concern was the reported belief that schools obtained the funding and could make decisions about how this funding would be used within the school – one parent told them the school suggested purchasing sporting equipment as they considered this a higher priority. It is also the view that funding for a support worker enables the classroom to have a support worker but they may not be focussed on the child that the funding is related to – they will be 'an extra pair of hands' for anyone in the class. Whether this is the case or not, it represents a view that parents consider their child with a disability is not valued in the education system.

The process for applying for support funding in education is incongruent with other support funding. Parents/carers caring for children living with rare conditions are used to navigating the health and disability sectors where they apply for the services or funding they need to support their child in the way they consider is required based on their expert understanding of their child. Education removes the expertise of the parent and creates a power imbalance where they become the arbiter of how much funding is required and how it is applied. This approach appears to be inconsistent with the Australian government education initiatives that focus on collaboration with parents such as the engaging parents in learning (2) and building family-school partnerships (3).

Harassment and victimisation

Sadly, the families and carers we represent do report harassment and victimisation. One family identified the only reason they knew their child was being harassed was because other parents of children involved advised them of the issue. This would suggest the school was both unaware of the issue and not managing it. More concerning, one parent reported that a teacher had laughed at their child because of their lack of physical agility in front of the class resulting in this being seen as acceptable by students who then joined in laughing at the child.

Compliance

Parent responses above indicate that many schools appear to be unaware of the Standards and how to meet them or are choosing to ignore them.

Parents routinely report that they consider because the Education Department investigates any complaint about a school there is a little chance a complaint will be upheld. A desktop review of the complaints upheld by the Australian Human Rights Commission suggests this view is reasonable. Between 2000 and 2005 there were only six complaints of discrimination upheld by the courts in relation to disability discrimination in education.

Information about how to make a complaint is available but the power imbalance in making a complaint is overwhelming, resulting in many parents choosing not to complain or not to take their complaint beyond a discussion with the school. This frequently results in parents moving their child to another school resulting in further disruption to the child and family and having to renegotiate the arrangements to support their child. Further, parents consider that there is little likelihood that the complaint will be favourably responded to as the complaint about the activity of the school is initially reviewed by the school and then the education department who have both a conflict of interest and a vested interest in complaints being withdrawn. We join the calls from parents and politicians in 2018 that suggest schools need their own ICAC that is independent to review complaints.

The Standards and their application should reflect the broader approach of the Department of Education and Training and include a focus on partnership, collaboration and well-being. Lessons from Health and Disability could be used to inform the approach to the application of the Standards. Parents need to be respected and viewed as the expert on their child, especially children living with rare conditions. These parents frequently know more about both the condition and the commensurate issues than medical and other professionals who may only see a handful of these conditions in their lifetime.

- (1) Anderson M, Elliott EJ, Zurynski YA. *Australian families living with rare disease: experiences of diagnosis, health services use and needs for psychosocial support*. *Orphanet Journal of Rare Diseases*. 2013. 8:22
- (2) <https://www.education.gov.au/parent-engagement-learning-0> accessed 22 September 2020.
- (3) <https://www.education.gov.au/parent-engagement-children-s-learning> accessed 22 September 2020.
- (4) <https://humanrights.gov.au/our-work/disability-rights/projects/education-and-disability>
- (5) <https://www.theeducatoronline.com/k12/news/schools-need-own-icac-for-abuse-complaints/238852>