8 September 2020

Save Our Sons Duchenne Foundation Submission to the Federal Department of Education, Skills and Employment.

2020 Review of the Disability Standards for Education 2005

CONTENTS

“You Just Have to Be Ahead of the Game”

(Mary from Victoria and mother of boy with Duchenne).

Executive Summary:

This submission was drafted in close consultation with the Duchenne and Becker community in Australia.

That education is of equal importance to the life chances and quality of life of young people suffering from Duchenne and Becker muscular dystrophy as it is to those who are not afflicted by this terrible condition, is uncontestable. On that basis alone, it is critical that mechanisms like the *Disability Standards for Education 2005* (the Standards) are fully operationalised and able to deliver on the high order objectives which are designed to ensure equivalence in educational access and opportunity for all young people whether disabled or not.

Via our own extensive research and consultation processes, SOSDF has formed the view that these Standards are continuing to play an important role in our education system. However, and importantly, it does appear that these Standards are only “given real life” and application through the tiresome advocacy efforts and the sheer determination of parents and carers who are seeking a “fair go” at school for their children with Duchenne and Becker.

From our consultation, it has become apparent that the role of the Standards turns too much on:

i) the particular School Principal and School leadership and whether they are committed or not to principles of inclusion;

ii) the capacity and energy of parents and carers to get organized, “make noise” and regularly provide clear guidance/instruction and checklists to Principals and teachers on the needs of their particular child/ren;

iii) whether good lines of communication (and opportunities for participation) have been established between school administrations and individual parents and carers, and finally;

iv) the amount of funding and resources specific Governments (and their school systems) are prepared to provide toward the provision of reasonable adjustments, teacher numbers, teacher training, teachers’ aides/learning supports within schools.

Introduction to SOSDF:

The Save Our Sons Duchenne Foundation (SOSDF) welcomes the opportunity to provide a submission to the Federal Government’s review of the *Disability Standards for Education 2005.* We believe the current 5-year cycle of review processes to be absolutely necessary in ensuring that these Standards continue to be relevant, contemporary and actively utilised in the equalisation of education opportunities between young people with a disability and those without disability.

Who we are?

SOSDF was founded in 2008 and is the peak body for those living with Duchenne and Becker muscular dystrophy (around 1,000 young people) across Australia. Our vision is to find a cure for Duchenne and Becker muscular dystrophy whilst actively working to ensure enhanced quality of life (including quality of educational opportunities) for those young people and their families affected by this condition. Advocacy and community engagement work are crucial to achieving this vision along with ongoing fundraising and events management designed to raise funds for essential research, service delivery and the provision of critical resources and equipment to the Duchenne and Becker community.

Along with the funding of a critical nurses program in some of our major children's hospitals across Australia, SOSDF also delivers a telehealth nursing service, scholarship programs, critical equipment and resources (such as wheelchairs and scooters) and a number of initiatives and programs such as music therapy which are designed to enhance the quality of life, skills and social development of young people suffering from Duchenne and Becker. For more information on SOSDF and the (cruel) Duchenne and Becker conditions please refer to the attached web link www.saveoursons.org.au.

More recently SOSDF released the landmark McKell Institute report (refer https://www.saveoursons.org.au/introductory-video-save-our-sons-duchenne-foundation-keynote-report-into-duchenne-and-becker-in-australia/). This report provided a comprehensive summary of issues impacting the Duchenne and Becker community across Australia including but not limited to:

- the astronomical financial, personal and psychological costs involved with supporting a child/ren with Duchenne and Becker;
- lost wages/income as a consequence of carer responsibilities;
- bureaucratic and regulatory impediments associated with clinical trials and research more generally;
- issues with the National Disability Insurance Scheme;
- the (un) timely diagnosis of Duchenne and Becker; and
- the importance of coordination of care.

This report has now been effectively utilised to draw national political attention to the concerns of the Duchenne and Becker community with a number of issues now placed firmly on the political agenda.

As has been made clear in this keynote report and from widespread consultation with the Duchenne and Becker community over many years, Duchenne and Becker carers and families already contend with enormous additional care responsibilities and issues. Many of these issues involve access and full participation in the educational system and educational opportunities with education critical to the life chances of young people with Duchenne and Becker. Subsequently, SOSDF has recently prioritised consultation with members of our community for purposes of the current review of the Disability Standards process.

SOSDF Consultation Process:

SOSDF determined to consult as widely as possible with the Duchenne and Becker community in the preparation of this submission. Social media posts were initially organised encouraging the community's participation and comment in the review. Following this, a series of individual zoom consultations of 30-45-minutes duration were held with parents/carers and some allied health professionals across Australia. Finally, an on-line zoom discussion was held with parents/carers who indicated an interest in participation.

A series of questions were posed to those involved in the consultation, a copy of which is attached at the conclusion of this submission. These questions attempted to go to those key issues which were identified as part of the main focus of the Department's review.

There was limited consultation with young people with Duchenne and Becker with almost all consultation involving parents, carers and allied health professionals. This was largely due to practical issues in facilitating zoom discussions with the boys and their ages. That said, however, we are confident that the views expressed through our consultation process sufficiently reflect/encompass and were informed by the educational experiences of young people with Duchenne and Becker.

Our submission is structured along the lines of some of the core questions we posed with some **recommendations** to follow in the conclusion.

Consultation Outcomes:

1. **What has been your experience with accessing education? What was the process like to enrol in school or other education and were you happy with the outcome?**

Overall, it appeared that most families were able to access their school of choice and there were few roadblocks/barriers in place. However, it appeared that most families were well organised and prepared and knew what they were seeking before approaching particular institutions – for example, schools were chosen on the basis of layout, and "gut feelings" after preparatory conversations with the school Principal. One parent remarked that due to the (inaccessible) physical aspects of their local public primary school they determined to send their child to a Catholic School situated 50 minutes away.

It was generally a given amongst those we spoke to (and a recurring theme throughout our consultation process) that those who could advocate and speak up strongest generally secured the access and resources (reasonable adjustments) which were required to facilitate their child's participation at a particular school. To quote from the words of Juliana, an Occupational Therapist in WA who works with a number of Duchenne and Becker boys:

"Families who are able to fight/advocate are a lot more successful".

SOSDF suspects there are many (overwhelmed) families who are dealing with Duchenne and Becker who simply do not have the resources, energy or capacity to advocate (to the level necessary) for their child/ren in the education system. This was confirmed by Mary a mother of a boy with Duchenne in Victoria.

"Lots of parents are muzzled. Most go by what the school says. Speaking to other parents they don't push"

This is concerning as access to an educational institution and any provision of reasonable adjustments, appear to be heavily dependent on the ability of families to advocate. Furthermore, if barriers exist at enrolment, then it is probably indicative of the lack of support a child with Duchenne or Becker is likely to receive at that particular school moving forward. In the words of Juliana again:

"***Families don't get to pick where they go. If barriers exist at enrolment, then why fight all the time -families are already so energy and time poor".***

Access and the provision of support/adjustments also appear to be very contingent on the particular Principal at the school and the lines of communication (or not) which have been established by families with the Principal and head teaching staff- another recurring theme throughout the consultation process. Ross, a father from NSW, stated:

"If the Principal is on board then there are no dramas".

Christine a mother from Queensland also commented that:

"An open line of communication to the Principal is so important and not feeling like you are constantly pestering them".

Generally, it appeared there were few differences between accessing/enrolment in the public system and the Independent/Catholic School sectors. While most parents/carers talked highly of the Catholic system there were some notable exceptions including one father from NSW who commented:

"Support was very minimal. They kept sending my boy home, they couldn't deal with him. There was no plan in place and they just weren't on board. We took him out of the Catholic school and sent him to a public school and we can't praise them enough".

And then there was the story of one mum from Victoria who has been struggling for years to get a wheelchair ramp into her sons' Catholic primary school:

"We are butting heads all the time and they just keep putting things off".

Access issues amongst the selection of families we consulted appeared to become more acute with the transition to high school and the slow progression of the Duchenne and Becker conditions amongst their boys. The choice of school (the facilities, learning supports available, the approach of the Principal and teachers, the school culture) become more critical factors with the general decline in mobility and movement.

2. **Has your education provider/s made reasonable adjustments to ensure you or your child can participate in education?**

Overall, most parents/carers appeared satisfied with the reasonable adjustments implemented by their schools to facilitate the participation of their child/ren. A number of parents indicated that whatever they wanted they generally got (this appeared to be especially so in relation to the Catholic Education Office in some primary schools). That said, many parents/carers indicated it was still a hard struggle to secure these reasonable adjustments. Donna, a mother from Victoria, said:

"It wasn't easy. Had to be a strong advocate. You couldn't rely on the school. My son is a good communicator and that helps because we needed to identify what we needed".

Physical (reasonable) adjustments typically included but were not limited to:
- the creation of wheelchair ramps;
- handrails;
- steps at drinking taps;
- bidets in toilets;
- special chairs; and
- the provision of scooters.

Despite this positive feedback, the SOSDF consultation nonetheless identified a number of "war stories" and inconsistencies between schools with the general sentiment again being, that some schools "go over and beyond" what is required whereas others do the bare minimum - with inclusion of those with a disability an afterthought. Furthermore, that much again turns on your ability to advocate and create good lines of communication with the school leadership.

SOSDF heard, for example, from a father in NSW whose son has been unable to access the senior part of his school playground despite the fact his son is now in senior years at High School. Further, that his son had never attended a school excursion and was only ever asked about participation once he reached Year 10.

Attendance at school excursions, school camps, extra-curricular activities and school sporting activities and carnivals evinced a strong reaction from a number of parents and carers and suggested much more needed to be done by educational authorities by way of reasonable adjustments, to ensure those young people with Duchenne and Becker could participate on an equivalent basis to other students. Too often it appeared that, boys with Duchenne were left on the "sidelines" to amuse themselves during school sporting activity or denied opportunities to attend excursions/camps unless a parent/carer was able to accompany their child/ren.

On the flip side of this, SOSDF heard examples of how schools included boys with Duchenne and Becker in excursions but failed to make the appropriate adjustments and modifications to ensure the child's attendance was properly accommodated. Patricia, a mother from NSW, told us how her school failed to take proper account of some steps on a field trip to Botany Bay resulting in an accident when teachers were forced to carry her son in his wheelchair. This example also reinforced the critical importance of parental advocacy as Patricia was then able to address issues relating to her son's participation in all future excursions:

"Now, after making a verbal complaint with the new Principal, all excursions are thought out and planned with my son in mind, and a risk assessment is carried out weeks in advance with my input. The assumption that I will be available to assist my son on the day or with transport often determines whether or not he will be able to attend an excursion".

This same mother also relayed the following story to us which highlighted the lack of forward thinking in much school building design and works:

"Demountable classrooms have been built to accommodate the increase in school numbers. A few years ago, the demountable Italian classroom that is part of the curriculum for my son was built with 10 steps to enter the front door. I asked the staff how they expected my son to get into the classroom, I was told "he'll be right, he can just wiggle up and hold the rail". I asked what the requirements were to get a ramp installed and whether the school needed any supporting documents from medical professionals to assist with getting this done but I was told that a ramp would cost $20,000 and it would be a long process to get approved and built. I was advised to wait and see how my son coped. After 3 school terms of advocating for the ramp, it was finally built. I felt like I was a burden to the school.".

Patricia's reflection above also highlights the concern that many parents/carers of Duchenne and Becker have expressed -namely, that they feel they (and their child/ren) become burdensome on the education system because they are constantly required to advocate to schools to get particular measures/strategies in place. Much guilt appears to be associated with this.

The pooling of funding for reasonable adjustments in some school systems also meant that individual families had to fight to guarantee that their child/ren got the specific adjustments they required.

Finally, there were issues with the delivery facilities such as disabled car parking. Christine a mother from Queensland discussed how she was caught up in a bureaucratic "buck passing" exercise between her local school and the local Council over the provision of a disabled car parking facility at the front of her busy school. As the School failed to take responsibility for this issue, Christine was forced to ensure another adult always travelled with her with each school trip to assist with the safe drop off her son in a wheelchair.

3. **Have you or your child been appropriately supported during your/their education? This includes being able to access supports, including specialist resources.**

There was a very mixed response to this question from participants in our consultation. There were issues raised about the difficulties getting private therapists into particular schools and a number of issues going to the lack of (Duchenne and Becker) awareness/expertise in relation to teachers' aides and teachers more broadly.

Issues were raised about the lack of speech therapy in special needs schools and inadequate resources provided to young people (such as laptop computers).

Questions were also raised as to whether young people with Duchenne and Becker were getting equal access to the training opportunities, work experience and TAFE pathways delivered by high schools.

Issues were also raised by those who were knowledgeable of the Disability Standards for Education about the failure of the Standards to cover before-and-after school care provided at schools -meaning many working parents and carers from the Duchenne and Becker community are disadvantaged if reasonable adjustments are required to facilitate the participation of their child/ren in these out-of-school hour services.

Teachers having to manage large student cohorts often meant that the needs of particular boys with Duchenne and Becker were overlooked especially in the absence of sufficient teacher aides.

Some parents and carers believed schools would ignore their recommendations and suggestions prioritising the views of health professionals over and above their lived experiences of Duchenne and Becker. A mother from Victoria, complained that:

"School doesn't take my knowledge on board. They only want to listen to a health professional"

Finally, issues with the quality and quantity of information provided by schools to parents and carers for activities such as school camps was not always forthcoming. As one mum stated:

"The school is just not forthcoming with information about camps. We feel we need to go on the camps just so we know that he will be safe".

On a positive note, a number of parents explained that they were given access to the teaching cohort (usually on a once-off teaching term basis) to provide presentations on Duchene and Becker - to raise awareness and provide key information on the needs of young persons with Duchenne or Becker. These information sessions appeared to be critically important to ensuring that particular schools were more inclusive and cognisant of the needs of the Duchenne and Becker community.

4. **If You or Your Child experienced harassment or victimisation in an education setting what happened? What steps did your/their education provider take to address this? Were you satisfied with the outcome?**

Aside from some limited teasing, very limited harassment, or victimisation by other school students towards their child/ren was reported by participants in our consultation. Interestingly, some teasing and bullying of the siblings of children with Duchenne and Becker was raised. The prevalence of this sort of unacceptable bullying behaviour may be higher than what was conveyed throughout this consultation.

Where some issues existed, parents and carers reported that the school would usually be adept at taking prompt action to stamp it out. Bullying/teasing were also rationalised by parents and carers as other students simply not understanding the condition affecting their child/ren -again pointing to the importance of raising awareness of Duchenne and Becker amongst the school community.

However, on the downside there were some concerning examples where parents and carers alleged that teachers had harassed or antagonised their child/ren. Stories were told of teachers talking down to their child because "*they look younger and are in a wheelchair*" (Dean, a father in NSW) and/or baiting their child/ren to set them up for failure. According to one mother who preferred not to be identified:

"The teacher my son had in year 3 would constantly antagonise him, set him up to fail and make comments such as "xyz won't say hello to me and doesn't have social skills or X hasn't listened to my instructions again' in front of others which in turn would upset my child and make him lose focus which the teacher would loudly reprimand him for. The teacher did not read (or perhaps understand) any of the literature I provided about the cognitive and behavioural functions associated with Duchenne e.g., information is processed in smaller chunks with Duchenne boys so some key messages will need repeating. Now the Principal and I meet at the end of the year and determine which teacher would best suit my son's academic needs for the next year".

Subsequently, with increased teaching awareness and training on issues such as Duchenne and Becker muscular dystrophy, SOSDF believes that the Disability Standards as they relate to bullying/harassment will progress further, in meeting their objectives.

5. Has COVID-19 impacted on your child's experience in participating in Education?

Consistent with the findings of the far reaching report undertaken by Children and Young People with Disability Australia (CYDA) *"More Than Isolated: the experience of children and young people with disability and their families during the COVID-19 pandemic"*, the Duchenne and Becker community experienced major issues participating in education as a consequence of COVID-19. This was especially so in relation to some of the key findings identified in the report (page 3), namely:

- Uncertainty about education including school closures and challenges with learning from home, and that progress gained by young people with disability could be lost during this period;
- Inability to obtain essential supplies e.g., groceries which were necessary for children and young people with a disability because of their conditions; and
- Cancellation of support workers.

More specific to the Duchenne and Becker community were:

- the higher health risks arising from COVID-19 as a consequence of their condition;
- limited access to teacher aides, educational supports and therapists during lock-down periods;
- additional learning needs which meant remote learning delivery was so much harder for parents and carers; and
- inflexible requirements to stay home (because of the higher health risks) when the rest of the school community had the option to stay/return to school.

According to Mary from Victoria:

"At least one day he needed to go to school. We need a break. We need a medical reason to say he can go to school. You just have to be an essential worker."

6. Are you aware of the Disability Standards for Education? If yes, how did you become aware of the Standards?

Almost universally the parents and carers of boys with Duchenne or Becker were unaware (or at best vaguely aware) of the existence of the Disability Standards for Education. This finding simply reflects the results of previous 5-year reviews (refer

Department's discussion paper) and the need for the Department, to do much more to promote awareness and understanding of their existence.

That said, it is clear to SOSDF that the Standards are positively impacting provided there are parental advocates who are pushing the school administrations and seeking to exercise the rights of their child/ren with Duchenne or Becker - to ensure equivalence in educational access and opportunities. So much would appear to turn on this in the absence of schools actively promoting and "marketing" the Standards to their respective school communities.

SOSDF is fortunate to have within its community, parents who are teachers and school administrators. We were heartened to learn that at least in some schools a module on the Disability Standards has been developed and is delivered as a teaching training requirement every couple of years. At those schools, negotiations with parents with child/ren with a disability is also encouraged to identify specific needs and requirements. Donna from Victoria, a teacher and mother with a boy with Duchenne maintains:

"The Disability Standards support inclusion. I can't see how we can tweak more. What's lacking is the communication side."

Finally, SOSDF notes that at the recent webinar organised by the Department of Education, Skills and Employment to kick-start consultation on the review, the overwhelming majority of participants to an on-line poll believed there should be mandatory training on the Standards for **all** educators. SOSDF firmly believes that mandatory training would certainly reduce the inconsistency between schools and teaching staff in the application of the Standards and would heighten awareness more generally of the need for inclusive pedagogical practices.

Aligned with this view was the position advanced in this consultation that whilst most teachers have good intentions, there was a lack of training regarding technology and the customisation of each child's needs to ensure they succeed i.e. "one size does not fit all", each child is different so customised processes and learning plans need to be developed. This is particularly so for those young people suffering from Duchenne and Becker muscular dystrophy.

7. **Do barriers still exist for students with a disability to access and participate in education and training? If so, how do you think the Standards could be improved to help address these barriers?**

Most, if not all participants, were of the view that barriers remained for their child/ren in accessing and participating in education and training.

Some barriers which were nominated included:

- lack of knowledge by the broader school community of particular conditions such as Duchenne and Becker;
- insufficient training/awareness of teacher aides/learning support staff;
- "hit and miss" nature of teachers -some were seen as responsive, others were not;
- physical infrastructure and facilities of schools;
- parents and carers who were not aware of their rights;
- failure to make school excursions, sports carnivals inclusive; and
- funding or resources for specific conditions such as dyslexia, ADHD.

Then there is also the "mushroom effect" with school administrations keeping parent and carers of child/ren with Duchenne and Becker in the dark. To quote from a mother from Victoria again:

"Parents are not aware of what they can access. If you don't ask, you don't know. Lots of shit shovelling is required".

In relation to teachers' aides, insufficient numbers were cited as a major barrier to an inclusive education by a number of parents and carers. A mother from Victoria, has three boys with Duchenne, one of whom also has ADHD. She commented in relation to teachers' aides:

"In terms of his academic studies they will give him one (a teacher's aide) but then take them away. They don't provide an aide consistently and he needs someone constantly".

SOSDF therefore notes with some alarm a series of recent articles in the Sydney Morning Herald *"Schools Must Prepare for 50 per cent rise in students with disabilities: report"* (https://www.smh.com.au/national/nsw/schools-must-prepare-for-50-per-cent-rise-in-students-with-disabilities-report-20200902-p55rrm.html) and *"Schools forced to address deficiencies in health system, professor warns"* https://www.smh.com.au/education/schools-forced-to-address-deficiencies-in-health-system-professor-warns-20200903-p55s6x.html?btis

These articles highlighted the growth in the number of students with disabilities and the need for twice as many specialist teachers and thousands more support classrooms. These articles go on to say that mental health experts are calling for a major investment in disability support staff, training, and resources for schools.

"Under a status quo scenario, the specialist teaching workforce would need to increase from 12,000 to between 19,000 and 23,000 in 2027, the BCG report said. However, such teachers were in short supply; ***only 56 per cent of learning and support roles in mainstream schools were filled permanently****" (SMH 3/9/20 Page 3).*

Finally, these articles also highlighted the huge increasing workload on an over-stretched teaching workforce as the profession grapples with new, competing and complex demands. As Professor Ian Hickie explained to a Teachers Federation Inquiry into the changing role of educators over the past 15 years. *"[Teachers have] become pastoral, they've become parental; social workers, psychologists, neuroscientists,"*. (SMH 4/9/20 page 13).

With such increasing demand on our educational system and our teachers and our aides/learning support staff, the totally inadequate resourcing and staffing of schools all-round, what chance do boys with Duchenne and Becker really have in navigating/participating on a level playing field in our current education system?

8. ***What are your views on moving to a completely inclusive education system where there are no longer any special needs classes and units in mainstream education?***

As part of our consultation process, SOSDF was interested to test the views of the Duchenne and Becker community on this question given the recent report by the Australian Coalition for Inclusive Education titled *"Driving change: A Roadmap for achieving inclusive Education in Australia".*

While SOSDF is broadly supportive of the alliance and the push to a totally inclusive education system, (with no segregated specialist schools, support units etc) we acknowledge and respect the fact, that amongst our community there are very mixed views going to this.

Our consultation demonstrated that all parents and carers want the mainstream education system to be as inclusive as possible – reflecting the importance of mechanisms such as the Disability Standards. Most parents, carers and young people clearly do not want to be part of segregated and separate education systems and schools.

Parents and carers however emphasised the importance of **choice** and the ability to be able to decide (without coercion or the imposition of access/enrolment barriers) which school their child/ren would attend. Donna, a mother from Victoria, commented:

"Don't know that I'm fully supportive of a completely inclusive system. There needs to be choice. The mainstream sector is too confronting for many of our community particularly in high school years. We need to respect the wishes of the child and their choice".

A number of parents and carers indicated that much depended on the level and nature of the disability, and there was also a clear distinction drawn between physical disability (where the mainstream was largely advocated) and intellectual disability where the provision of specialist schools was seen to be more necessary.

Juliana, the occupational therapist from WA, said:

"With the right set up physical needs are much easier to meet. All of my DMD clients go to mainstream schools and that is what they want. For those with intellectual disabilities however it is more complex and special schools are required".

Full inclusion in the mainstream education system is clearly more challenging as the boys advanced through high school and their conditions deteriorated with age.

RECOMMENDATIONS:

1. **That the Department move to ensure that the *Disability Standards for Education* are applied to before-and-after school care programs run within the various School systems;**

2. **That greater efforts and endeavours are made by the Department to ensure all parents and carers are made fully aware of the existence, role, function and application of the *Disabilities Standards in Education;***

3. **That the Department mandate training on the *Disability Standards for Education* for ALL teachers and educators (on an annual basis) and that such training become core to ongoing teacher professional development – and not an afterthought and simply provided at the margins.**

4. **That greater teacher and teacher aide training be provided into various disabilities and conditions such as Duchenne and Becker to ensure the needs of young people suffering from these conditions are recognised, "customised" and accommodated in the education system -and not overlooked as a consequence of wider student cohort management issues;**

5. **That greater involvement and participation of parents and carers with child/ren suffering from a disability be facilitated in the design and layout of any new school buildings and facilities;**

6. **That regular and more formal consultations be scheduled between School Principals/staff and families with children with Duchenne and Becker, to ensure that specific learning and adjustment needs are being met and across the education system -without continued reliance on the capacity of individual parents and carers to advocate;**

7. **That the Department consider a specific consultation with the Duchenne and Becker community to better understand needs, requirements and aspirations of the community as it relates to the education system;**

8. **That the levels of teacher aide and educational support be increased to the Duchenne and Becker community during any future lockdown arising from the COVID-19 or other health pandemics;**

9. **That a review be undertaken by the Department into the inclusion/exclusion of young people with a disability (inclusive of Duchenne and Becker) in school excursions, school sporting activities/carnivals and extra-curricular activities delivered by schools;**

10. **That a representative of the Duchenne and Becker community be invited on to any steering committees, working parties, consultative committees or forums which are charged with overseeing the operation and implementation of the *Disability Standards for Education.***

11. **That there be a significant injection of funding into our education system to increase teaching numbers and resources to ensure that the needs of all young people with a disability are fully met and that educational opportunities are truly equal for all. Furthermore, to increase teaching numbers to ensure teachers and School administrations are not overworked and overwhelmed by the increasing and complex needs, demands and requirements of students and their families.**

Lance Dale **and** **Patricia McPhail**

Advocacy Officer/SOSDF **Community Engagement Officer/SOSDF**

References:

1. Australian Coalition for Inclusive Education "*Driving Change: A Roadmap for achieving inclusive Education in Australia*".
2. Sydney Morning Herald 3/9/2020 "*Schools Must Prepare for 50 per cent rise in students with disabilities: report*"
3. Sydney Morning Herald 4/9/20 "*Schools forced to address deficiencies in health system, professor warns*"

4. Children and Young People with Disability Australia (CYDA) *"More Than Isolated: the experience of children and young people with disability and their families during the COVID-19 pandemic"*
5. Federal Department of Education, Skills and Employment *"2020 Review of the Disabilities Standards for Education 2005: Discussion Paper"*.
6. McKell Institute *"Living with Duchenne and Becker in Australia: Supporting Families Waiting for a Cure"* April 2020.

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Attachment One

Questions which framed the consultation discussions

1. **What has been your experience when accessing education? What was the process like to enrol in school or other education and were you happy with the outcome?**

2. **Has your education provider/s made reasonable adjustments to ensure you or your child can participate in education?**

3. **Have you or your child been appropriately supported during your/their education? This includes being able to access supports, including specialist resources**

4. **If you or your child experienced harassment or victimization in an education setting what happened? What steps did your/their education provider take to address this? Were you satisfied with the outcome?**

5. **Has COVID-19 impacted on your child's experience in participating in education?**

6. **Are you aware of the Disability Standards for Education? If yes, how did you become aware of the standards?**

7. **Do you feel like you understand you or your child's rights when it comes to being able to access and participate in education? If not, what can be done to improve awareness?**

8. **Do you think the standards help students with disability to access and participate in education and training on the same basis as students without disability? Why or Why not?**

9. **Do barriers still exist for students with disability to access and participate in education and training. If so, how do you think the Standards could be improved to help address these barriers?**

10. **What are your views on moving to a completely inclusive education system where there are no longer any special schools or special needs classes and units in mainstream school?**

11. **What would be required to ensure all young people with a disability are able to participate equally along with young people without a disability in mainstream education?**

12. **Would you be prepared to provide us with examples regarding you or your child's experience of the education system which we could utilise in our submission to the Federal Government? This information would be de-identified.**


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