

**Submission  
No 116**

**INQUIRY INTO PLANNING AND DELIVERY OF SCHOOL  
INFRASTRUCTURE IN NEW SOUTH WALES**

**Organisation:** Save Our Sons Duchenne Foundation

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## **Save our Sons Duchenne Foundation Submission:**

**To:**

### **NSW Legislative Council Portfolio Committee No 3 - Education**

### **Inquiry into the Planning and Delivery of School Infrastructure in NSW**

*“Policies need to be closely examined to ensure inclusivity and appropriate care for all students- the emergency plan at our local high school stated that in an emergency anyone who could not use the stairs (ie, wheelchair users) would be placed in the accessible toilet upstairs (as the lift would not work). I explained that under no circumstances should this happen to my son in the event of fire or emergency and that they should perhaps test run it on the Principal before using it on students”.*

A mother of a young man with Duchenne from South Western NSW.

#### **Introduction: *On the importance of planning for inclusion***

The Save Our Sons Duchenne Foundation (SOSDF) thanks the NSW Legislative Council Portfolio Committee No 3 -Education (“the Committee) for the opportunity to provide a submission to the Committee on the Inquiry (“the Inquiry) which is reviewing the current planning and delivery of school infrastructure in NSW.

Ensuring that young people with Duchenne (DMD) and Becker (BMD) muscular dystrophy are fully included in school life and educational opportunities is fundamental to the quality of life and life prospects of those afflicted with this debilitating and terrible disease. SOSDF views the planning and delivery of school

infrastructure and facilities as fundamental to issues of inclusion, with the capacity to “make or break” the experience of school for these young people.

Properly designed and delivered infrastructure and facilities can help address structural and social barriers and disadvantage encountered by these young people during their journey through the educational system - whereas infrastructure, (eg, inaccessible facilities, poor building design) which are not cognisant of the needs of those with disability or rare diseases, can simply lead to further exclusion and a poor educational outcome. The following story relayed by a parent of a young man with Duchenne from country NSW, highlights the deleterious impact of poor planning and infrastructure:

*“The Community Hall that the school uses for Presentation Day does not have an accessible stage. So if the presenter comes down the steps to floor level we know that our boy is about to get an award! While this allows him to be included it does make it “different” to the rest of the school. It also makes it “different” for his classmates as they award all his class on the floor level if our son is one of the recipients. No-one has ever said anything to us, but I’m sure the other parents would prefer their students “on stage”.*

Given the importance that SOSDF and our community places on schools which are planned to be inclusive of young people with disabilities, we have chosen to participate in this Inquiry recognising the need for our community to have some voice in this important inquiry consultation process.

This Inquiry also provides an invaluable opportunity for SOSDF to raise the argument that school infrastructure planning and investment which does not prioritise or sufficiently address the needs of students with a disability or rare disease (and ensure an inclusive educational experience) is INADEQUATE and falls well short of our international human rights obligations as they pertain to people with a disability (*UN Convention on Rights of Persons with a Disability*).

***Submission structure:***

This submission will not attempt to address all of the Inquiry Terms of reference (TOR) and will instead, concentrate on reinforcing those issues which are important to our community and which they would like to highlight to Committee members.

The comments which follow have been formulated following a consultation with interested members of our community whose children have DMD/BMD and are attending either a public primary or high school in NSW.

A copy of the questions which we used for our community consultation purposes appears at **attachment one** of this submission.

## **Who We Are?**

The Save Our Sons Duchenne Foundation is the peak body representing the Duchenne (DMD) and Becker (BMD) muscular dystrophy community in Australia. DMD and BMD are genetic and progressive muscle wasting conditions which affect 1 in every 3,500 boys and in rare circumstances, some girls in this country. These conditions result in the loss of ambulation (typically at a very young age) and the continued decline in all muscle usage until sadly, untimely and premature death results.

Our organisation which has been in existence for over 13 years, is battling to find a cure for this condition. SOSDF has subsequently been instrumental in funding clinical trials, leading research projects and a neuromuscular and clinical nurse's program at several children's hospitals across Australia. In addition, the organisation develops a range of community programs/resources and is actively undertaking systemic advocacy work on behalf of the community we are representing.

Save Our Sons Duchenne Foundation has also established a range of innovative fundraising and marketing events which aim to not only raise money to fund nurses, clinical trial staff, quality of life/community initiatives and research, but also, to raise community awareness of the Duchenne and Becker conditions.

For more information on SOSDF and Duchenne and Becker muscular dystrophy please refer to our website at [www.saveoursons.org.au](http://www.saveoursons.org.au).

### ***Comment on existing education policy/plans and legislation:***

*While the Federal Disability Standards in Education 2005 is critical to ensuring that young people with disabilities are not discriminated against in the education system, our own research demontsrated that these standards are inconsistently applied across the education system and do not appear to impact some (bigger) infrastructure planning issues.*

In late 2020, SOSDF participated in the Federal Government's five year review of the Disability Standards and found that the application of these standards varied between schools and sectors with too much turning on the advocacy efforts of parents/carers and

the prioritisation given to inclusion matters by individual School Principals and administrations.

*In the SOSDF submission to this review, we concluded 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.*

*Save Our Sons Duchenne Foundation 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”.*

A full copy of this submission is **attached** for the Committee’s information.

The *Disability Standards in Education 2005* are also largely ineffectual when it comes to major infrastructure or facility work in schools. Under the Standards, education providers are able to opt out of requirements going to a<sup>2</sup>reasonable adjustment if it would impose an **unjustifiable hardship**. For cash strapped schools in the public system which may have been in existence for many years, major renovations or infrastructure work to ensure appropriate access and inclusion for students with a disability, may be a major financial challenge and simply viewed as unsustainable.

The Save Our Sons Duchenne Foundation notes the NSW Department of Education’s current “*Disability Inclusion Action Plan 2021-25*” and what appears to be a concerted endeavour to improve inclusion and educational opportunities for those with a disability. According to the Department of Education:

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<sup>1</sup> SOSDF Submission “2020 Review of the Disability Standards in Education” Page 8.

<sup>2</sup> Disability Standards in Education Fact Sheet 2. [Fact Sheet 2: Disability Standards for Education 2005 - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](https://www.dese.gov.au/fact-sheet-2-disability-standards-for-education-2005)

*“<sup>3</sup>This plan articulates a consistent, achievable approach to improving outcomes for people with a disability. Not as a separate and bespoke strategy, rather as an important central part of our everyday business.*

#### *Our intent*

*Although DIAPs currently have a four-year lifespan, they must become integrated into organisational culture and practice. To achieve this, we commit to embedding the principles of inclusive design in our thinking and actions. We will listen to, learn from and codesign with our stakeholders to:*

- be constantly aware of, proactive and responsive to disability matters.*
- take deliberate steps to identify challenge areas and take planned and resourced actions to address them. These steps will come in the form of projects.”*

The plan outlines a number of key focus areas including Focus 3 (*Our physical places and spaces*) and highlights the need to *embed universal design to embrace diversity and deliver design solutions that benefit as many people as possible and afford users the dignity of independent and equal access.*

This focus area is highly commendable and appears to build on the previous *Disability Inclusion Plan 2016-2020* where actions were developed (<sup>4</sup>refer focus Area 2: *“Creating more Liveable communities for people with a Disability”*) to ensure Schools buildings were more accessible.

With focus areas in both the current and past disability inclusion plans highlighting increased access for students with a disability, SOSDF believes that the Department’s progress in meeting these key objectives/actions should be reviewed during “part and parcel” of this Inquiry.

The Save Our Sons Duchenne Foundation is also concerned to ensure that the facility and infrastructure shortfalls of older well established educational institutions are addressed – after all, many young people with DMD/BMD (or other disabilities) live in established areas with established educational institutions or alternatively, they are not able to attend a modern school with contemporary accessible facilities. We would therefore hope that the Disability Inclusion plan has given an equal weighting to both new and existing school infrastructure.

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<sup>3</sup> <https://education.nsw.gov.au/about-us/strategies-and-reports/our-disability-inclusion-action-plan>

<sup>4</sup> NSW Department of Education, “Disability Inclusion Plan 2016-2020” Page 10.

On an anecdotal level, SOSDF understands that there is also legislation in NSW to ensure building modifications in Schools do occur. Unfortunately, we have heard from some in the education sector that this renovation work is often very slow, not particularly responsive, and mired in mountains of bureaucratic paperwork . This was a common complaint from a number of our community members who often felt frustrated by the slow pace of building/renovation progress once building/facility works had been identified. Said one father of a boy with Duchenne when asked if he had attempted to raise the lack of specific facilities with the School Administration:

*“Yes. Individually most teachers and school leaders are supportive and try to do what they can. However, the rules and the processes as well as the limits of available funding often restrict meaningful outcomes, and generally take a lot of time (eg, the next year).”*

### **Terms of Reference (TOR):**

- 1. (b) the adequacy of plans by the NSW Government to deliver educational facilities for every NSW public school student:**
- c) the adequacy of investment in new or upgraded infrastructure at existing NSW public schools and in new school projects.**

*“School excursions and other events need to be carefully planned to ensure inclusivity. Even simple things like “Clean up Australia Day” should be thought about in advance. My son was left at school with kinder when he was in Year 4 as he was still self-ambulatory and would be “too slow”. He was extremely upset, had we known I would have organised a friend or one of us to go with him and walk along behind his stage group. Buses without access have ruined many a trip because of poor planning”.*

Mother of a boy with Duchenne from Western Sydney.

In an attempt to address these TORs, SOSDF consulted with families and young people about what (baseline) facilities and infrastructure was required to ensure adequate inclusion in education institutions. The following is a list of some of those facilities/issues the DMD and BMD community highlighted (some of these are resources and not physical requirements) and which were thought to be critical in planning deliberations on School infrastructure and facilities.

- No steps into classrooms or the provision of wheelchair ramps or lifts in multistorey buildings, where this is unavoidable;
- Accessibility to all common areas such as playgrounds, halls, canteens etc;

- Ramp access to computer labs, library, stage;
- Disability parking spaces which are appropriately located and safe for entry and dismount;
- All walkways to be covered;
- Widened doorways into every room;
- Air conditioning in all rooms to ensure comfort (boys with Duchenne get very cold and very hot easily);
- Several disability accessible only bathrooms around the school that don't have general access, and have automatic door openers;
- Height adjustable furniture (eg, desks, smart boards etc);
- Straight hallways and corridors;
- Flat entry to all areas;
- Adequate natural lighting, ventilation, cooling and heating;
- Occupational therapists/physios and other applicable "experts" should be an integral part of any infrastructure planning and implementation phase;
- Independent Learning Plans (ILPs) for each student that account for any modifications needed in relation to the academic, physical, social and emotional needs of the students – we understand these are currently a mandatory requirement but often do not happen;
- Wheelchair accessible vehicles for excursions, sporting activities etc;
- Full consultation with families and young people to ensure the exact infrastructure/facility needs of the individual are met (not a one-size fits all approach).
- Provision of teacher aides with specific knowledge and experience of DMD/BMD.

Once this list was identified, SOSDF explored with families and young people with DMD and BMD whether these facilities and infrastructure were currently available in their respective school and whether adequate planning had taken place. We received a very mixed response.

Says one mother with a boy with Duchenne who also works as an educator:

*"Schools are often old and designed well before thoughts of inclusivity and wheelchair access, so a creative approach is often required. The primary school my son attended was modified in line with his needs. As a teacher I knew to ask about these well ahead of him actually needing them.*



*Unfortunately, this “change as you go approach” is often impaired by the slow process of administration”.*

Then there is the following from a father of a boy with Duchenne from Sydney:

*“When a teacher is away students get moved to other rooms. There have been a few times they have sent him to a room with steps (eg, a demountable room) even though we have said not to. This has led to him falling down the stairs.*

*We have also asked to have a room nearest to an accessible bathroom to minimise the time out of class. This hasn’t been the case for some years.”*

While recognising that the NSW Department of Education is attempting to address the infrastructure and facility needs of all NSW public school students, (as demonstrated by strategic initiatives such as the Disability Inclusion plans), SOSDF nonetheless maintains that we still have some way to go in infrastructure planning for students with disabilities and rare conditions such as DMD and BMD -as evidenced by our consultation process where families continue to highlight some of the real difficulties and physical barriers still encountered by their children at school.

In sum, more can be done in relation to the management and planning processes of school infrastructure to ensure the needs of people with a disability are fully factored in, and that building works are expedited in a more timely fashion as needs arise. Further, it should be recognised at all levels of policy making, that the design, construction, maintenance, budgeting and expenditure on new infrastructure projects should not only meet the needs of able bodied students but those with physical/intellectual incapacities and rare disease conditions – to ensure that these young people experience education on an equivalent level to their able bodied peers and that any disadvantages are not further accentuated.

And while there are clearly financial/budget limitations, SOSDF believes more prioritisation of the needs of students with a disability should be given in the infrastructure planning and delivery process for our schools -both in the planning for new schools and in the renovation/restructure of existing educational establishments.

As one parent of a boy with Duchenne pointed out, accessible facilities will not only ensure a more inclusive school environment but will have positive offsets for the wider school community:

*“I think all school facilities should be accessible-not only does this make them inclusive for students that need it but it makes them so much more user friendly for parents with prams, elderly visitors and students with short-term disabilities”.*

**1.d) the role of local community organisations and groups in responding to the lack of or shortage of educational facilities at any NSW Public school especially in areas of high growth and in proposed new suburbs**

While this TOR goes to role of local community organisations and groups, SOSDF seeks to highlight the critical role that parents/carers of boys with DMD/BMD have played in responding to the lack or shortage of accessible facilities and infrastructure in specific schools. During our consultation process we repeatedly heard about the critical role parents/carers had been playing to ensure a shortfall/gap in facility/infrastructure was being met – this being consistent with the findings of our earlier research into the *2020 Disability Standards in Education*.

This (advocacy) role was performed with respect to old existing infrastructure and also the planning for new school infrastructure. Highlighting the importance of this role one father with a son with Duchenne explained:

*“Our son has attended John Palmer Public School and the Ponds High School. Both schools are relatively new builds (JPPS 2008 and TPHS 2015) and wheelchair accessible. On a site visit to TPHS last year in anticipation for his attendance this year we identified that the two disabled bathroom doors were too heavy for him to access on his own. Arrangements were made to install automatic door openers to the two disabled bathrooms. This is the first year (2022) that students in wheelchairs have attended.*

*Both schools have been more than accommodating with our son’s needs putting into place everything we ask of them. The main response back from School Admin is about the amount of red tape they have to go through with the Department of Education to facilitate the changes”.*

***On the need for more consultation:***

Rather than improvements in school infrastructure/facilities turning on the efforts of individual family advocates, the Department of Education needs to ensure that representatives of the disability community are actively engaged at all stages of the planning and delivery of school infrastructure.

In addition, more consultation with families and young people with disabilities need to occur where schools are seeking to address existing building flaws and undertake renovation/restructuring. Unfortunately this does not always appear to be the current practice in NSW which is inconsistent with the recognition of stakeholder roles and involvement (including co-design) espoused in the Department’s *Disability Inclusion Plan 2021-2025*. Says one mother of a Duchenne boy when asked if she was consulted about school construction/design upgrades:

*“Not in any of the major construction upgrades such as ramps. Would have been good to be consulted as even without “disability” knowledge there were better placement options ie: out of the rain! Or to take up less space in design:*

And this from another mother of a young boy with Duchenne:

*“The placement of the large number of ramps that were needed was decided by our Principal and a Dept of Ed properties manager, no school staff or parents/student with a disability were included. Staff and parents feel that consultation there would have been much easier, cheaper and ergonomic placement of the ramps available”.*

Consultation practices need to be strengthened at all levels and irrespective of whether the Government (through the Department of Education) is designing whole new schools or renovating existing facilities. We must avoid situations such as those described in the following two scenarios by two mothers of sons with Duchenne:

*“I am fortunate (or loud enough) to have been included in lots of planning meetings and feel that this is an essential place for families to have a voice. I remember talking to the guy in charge of modifying the school playground in high school. He said “don’t worry” I know all about wheelchairs”. I replied that this might be true, but he knew nothing about my son. It turned out that the path was quite safe for a manual wheelchair with an attending support person, not so much for a 15 year old with a power wheelchair that could travel at 10km per hour”.*

Mother of son with Duchenne from the far west of NSW.

*“Our school is getting an upgrade with new portables and the possibility of a lift which our principal pointed out to me late last year that she made sure was going to be a lift for my boy. I just walked away thinking it is not a lift for my boy. It is actually called UNIVERSAL ACCESS” I don’t understand why they don’t or won’t think like this. We used to have 10 steps to the canteen shop window so I’m not sure if there has been any consideration for making the new canteen structure accessible to all. I have not been involved with any planning or consultation. I just hope and pray that he will get through Primary School without having to use a wheelchair but I could just be clutching at straws.”*

Mother of a son with Duchenne from north coast of NSW.

In addition to establishing structures and forums to ensure that the parents/carers of young people and other disability representatives are adequately informed, consulted and participating in the planning processes for the delivery of school infrastructure, SOSDF believes that more training on disability awareness and the disability standards in education could be implemented for some of our more senior educators and administrators.

## 1. (h) school design that promotes health and safety:

The Save Our Sons Duchenne Foundation would argue that a school which is designed to ensure the full inclusion of students with a disability, is a school that promotes health and safety. It is a school environment which will enable students with a disability to flourish rather than simply experience more barriers, withdrawal and (potentially) psychological harm.

Consistent with the above, parents/carers and representatives of the wider disability community should be involved where appropriate and feasible in the design and implementation phases for new school infrastructure and facilities. In addition, the advice and input from those with specialist disability and rare disease knowledge, such as occupational therapists and other allied health professionals should be actively sought in design issues. This was something recommended by a number of our families. Suggested one father with a son with Duchenne attending a public school in Sydney:

*“.....maybe an OT could be placed at a regional level within the Department of Education to provide input in their decision making stages and also attend schools and conduct assessments for new students/when the need arises to also educate staff and have the ability to fast track infrastructure changes”.*

In sum, SOSDF believes that a school which delivers/implements the sort of items identified earlier by the Duchenne and Becker community under TOR 1 b) & c) is a school with a clear agenda (and capacity) to promote health and safety for ALL students, inclusive of those with a disability.

The Save Our Sons Duchenne Foundation subsequently recommends that the Department of Education undertake a widespread consultation and audit process to **firstly**, identify the baseline list of infrastructure/facility requirements for young people with disabilities and rare diseases (as our community has done in TOR 1 above) and **secondly**, an audit to establish where the gaps in this infrastructure currently exist. **Finally**, the Department should determine whether new and future planning processes have given sufficient weighting and prioritisation to addressing these gaps.

## Conclusion

*“Universal access should form the basis of infrastructure for schools and all public spaces”.*

Mother of a young man with Duchenne.

The contribution to this Inquiry by the Save Our Sons Duchenne Foundation has been made in good faith and accurately reflects the feedback we have received from families who participated in our consultation process. We have made a few recommendations below which pick up on the concerns and ideas of our community members-doubtless much of what is recommended may already be in place but we believe there to be no harm in re-stating what remains of importance to our community.

In our submission, we have consistently sought to reinforce the importance of infrastructure planning and implementation which is informed by the needs of people with a disability and rare disease conditions. The NSW Department of Education appears to have the right plans and initiatives in place and planning has progressed in more positive ways, but we say more can still be done to ensure universal access for all students at our schools.

The Save Our Sons Duchenne Foundation and our broader community wishes the Committee well in progressing this Inquiry and we are more than prepared to contribute further should the Committee wish to communicate directly with us.

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## RECOMMENDATIONS:

- 1) That the NSW Government give greater prioritisation to the needs of students with a disability and/or rare disease when planning and delivering new school infrastructure and facilities;
- 2) That the NSW Government through the Department of Education undertake a consultation with parents/carers of students with a disability or rare condition to determine a baseline level of facilities and infrastructure which should be provided in all new and existing schools - and which ensures universal access to ALL students;
- 3) That the NSW Government through the Department of Education, undertake an audit of all schools to determine what gaps (if any) exist in facilities and infrastructure in relation to the baseline developed in 2 above;
- 4) That as part of this Inquiry, this Committee review progress made in relation to the NSW Education Department's *Disability Inclusion Plans 2016-20, 2021-25* as they relate to the provision of school infrastructure and facilities which promotes and enhances universal access for all students;
- 5) That structures be established at local, regional and State levels to ensure that parents/carers of students with a disability and rare conditions (and representatives from the disability sector) have input into the planning, design and implementation phases of school infrastructure and facilities- for both new schools and existing ones;
- 6) That the NSW Government streamline the processes for expediting renovation/building works for any school facilities/infrastructure which is impeding universal access for all students;
- 7) That Occupational Therapists and other allied health professional with specialist knowledge and insights into disabilities and rare diseases be included in

planning and design processes for new and existing school infrastructure and facilities; and

- 8) That the NSW Department of Education provide more disability awareness training and training on the *Disability Standards in Education* to School Principals and senior School administrators.

## **BIBLIOGRAPHY**

1. SOSDF Submission “2020 Review of the Disability Standards in Education”.
2. Disability Standards in Education Fact Sheet 2. [Fact Sheet 2: Disability Standards for Education 2005 - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](#)
3. <https://education.nsw.gov.au/about-us/strategies-and-reports/our-disability-inclusion-action-plan>
4. NSW Department of Education, “Disability Inclusion Plan 2016-2020”.





