

**Save Our Sons Duchenne Foundation (SOSDF)
Submission to the
Queensland Parliamentary Inquiry
into
Social Isolation and Loneliness in Queensland**

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“Loneliness and Isolation are major factors for the Duchenne and Becker community. Duchenne muscular dystrophy is a rare disease and therefore it is challenging to find members of the local community who you can relate to and feel amongst your own. It is also incredibly difficult and isolating when there are very few activities and resources that a person living with DMD can use and you are forced to not attend and take part in various community activities that are easily accessible and catered to for able body people or people not in a wheelchair”.

A mother with a boy with Duchenne living on the Gold Coast.

Executive Summary:

This submission was drafted by Save Our Sons Duchenne Foundation (SOSDF) after extensive consultation with members of the Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) communities living in Queensland.

Social isolation and loneliness are huge issues impacting the DMD and BMD community in Queensland (and other parts of Australia). They are issues affecting the quality of lives of all young people and their family members, who are living with this condition which can exact an enormous toll on all personal, social and community facets of a person’s life. Social isolation and loneliness are compounded in the Queensland context by a range of factors which include but are not limited to:

- the lack of targeted services and service provision in Queensland which are geared towards groups with rare diseases such as DMD and BMD;
- the lack of connection experienced by the DMD and BMD community because of service gaps and opportunities more generally;
- the outdoor nature and culture of the Queensland community which is much harder for the DMD and BMD community to navigate and which continues to demonstrate variations in levels of inclusivity;
- inconsistencies in the education system with some Schools prioritising an inclusive culture and others marginalising it;
- the remote location of some families and the vast distances which are often required to be travelled for families and young boys/men with Duchenne to secure access to health,

- recreation and social activities and the inadequacies in some of the transport infrastructure (e.g., airlines) which can be inaccessible or burdensome for wheelchair travellers; and
- lack of accessible facilities and equipment to promote inclusion. For example, beach wheelchairs, powerchair sports where modified wheelchairs are available (and not an additional financial burden on families), wheelchair accessible bars, clubs, gyms, cinemas etc.



Based on the above, the Save Our Sons Duchenne Foundation (SOSDF) welcomes the opportunity to provide a submission to the Community Support and Services committee (the ‘committee’) which is conducting the Queensland Parliamentary Inquiry into Social Isolation and Loneliness in Queensland (the “Inquiry”). While the terms of reference for this Inquiry are broad and extend far beyond specific rare disease communities such as the DMD and BMD community, SOSDF and the

community we represent, believes this Inquiry provides an excellent opportunity to raise in good faith, several key concerns and recommendations for consideration by Committee members. Further, our community believes such an Inquiry to be long overdue and we remain hopeful that some lasting and far-reaching outcomes can be achieved through this bi-partisan and constructive political process.

There are approximately 30 different genetic conditions that make up the muscular dystrophies and the severity ranges on a spectrum. *The most severe end of the spectrum is known as Duchenne muscular dystrophy lacking completely dystrophin protein. Decreased or truncated dystrophin protein is associated with less severe form is Becker muscular dystrophy. (<https://rarediseases.org/rare-diseases/duchenne-muscular-dystrophy/>)*

In the absence of a cure for Duchenne and Becker muscular dystrophy and with clinical trials; pharmaceutical; medical and technological advances extending the life expectancy of boys with the disease, it has become critical to ensure that the social isolation and loneliness burden experienced by this community is addressed and minimised to the extent which is possible. This Inquiry can play an important role in ensuring that these outcomes are achieved and that families struggling with this condition no longer must endure the barriers such as that described below by a mother of a boy with Duchenne from Brisbane:

“Accessibility is an issue. For example, lots of houses, playgrounds, cafes, bars, clubs, some gyms and shops cannot be accessed without going up/downstairs. The majority of people sit in the centre or back seats at the movies which aren’t usually accessible to wheelchairs.

Lack of shared activities contributes to feeling isolated e.g., difficulty in participating in mainstream sports. More shared activities would be helpful, not just classes for disabled kids. Also support for clubs/groups to be inclusive such as allowing a few adjustments e.g., Special seating.”

With the Paralympics and Olympic games scheduled for Brisbane in 2032 (ironically premier sporting events bringing the world community together) there would now appear to be a priceless opportunity for the Queensland Government to rectify any shortcomings in community infrastructure and facilities - as part of the Olympic construction and building works program. Wheelchair accessibility to all key social and recreational events should be prioritised as part of any Olympic building investment/works - in the process, allowing the State Government to showcase these progressive developments to the rest of Australia and ultimately, the world.



Who we are?

Save Our Sons Duchenne Foundation (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 health, educational, employment, social and recreational 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.

Save Our Sons Duchenne Foundation is a non-government Australian charity, who do not receive government assistance to represent the DMD/BMD communities as their peak body. We have raised millions of dollars for research and clinical trials, along with the funding of critical neuromuscular and clinical trials nurses' programs in most of our major children's hospitals across Australia, (including Queensland's Children's hospital in Brisbane). SOSDF also delivers a telehealth nursing service, scholarship programs, and prior to NDIS we funded critical equipment and resources (such as wheelchairs and scooters, cough machines) and a number of initiatives and programs such as teachers' information packs, music therapy, scientific conferences which are designed to enhance the quality of life, skills and social development/interaction and knowledge of young people suffering from Duchenne and Becker.

For more information on Save Our Sons Duchenne Foundation and the progressive muscle wasting disease of Duchenne and Becker please refer to the attached web link

www.saveoursons.org.au.

McKell Access Economics Institute Report:

Save Our Sons Duchenne Foundation is also responsible for major research projects such as the landmark Mc Kell Institute report "*Living with Duchenne and Becker in Australia: Supporting Families Waiting for a Cure*" which was commissioned in early 2020 (a full copy of this report is **attached** to this submission - please also refer to:

<https://saveoursons.org.au/blogs/advocacy/introductory-video-save-our-sons-duchenne-foundation-keynote-report-into-duchenne-and-becker-in-australia>

This report which aside from identifying issues around the lack of clinical trials and new medical/treatment options for the Duchenne and Becker community in Australia, provided a comprehensive summary of issues impacting the Duchenne and Becker community, including the astronomical financial, personal and psychological costs involved with supporting a child/ren with Duchenne and Becker.

¹According to this report, which was launched by a number of parliamentarians in Canberra in September 2020, Duchenne in particular, is associated with significant lifetime health and social care costs. It is estimated that these can total up to \$2.25 Million for a child living until their mid-thirties. In addition, informal care costs total up to \$630,000 in terms of reduced female participation in the workforce. On average, the financial cost of Duchenne for a child born today are expected to be \$1.3 million. However, the costs for a child living to their mid-thirties rise to \$2.88 million.

²Families who participated in the McKell research typically reported high out of pocket medical costs, ranging to \$1800 per month.

The costs (and time invested) of caring for boys with DMD and BMD clearly puts enormous strains on family budgets and will subsequently limit opportunities and the time available for many personal, social and recreational activities -compounding issues of isolation and loneliness. As the McKell research also discovered having a child with a rare disease can also be an extremely isolating and lonely experience with other parents having no real understanding or appreciation of the lived experience of Duchenne and Becker. In the words of one mother with a boy with Duchenne who was interviewed as part of this research project:

¹ McKell Access Economics Institute Report Pages 14, 44

² Mc Kell Access Economics Institute Report Page 22

³Having a child diagnosed with a rare condition is often a confusing and lonely experience. Unlike other aspects of parenthood those in your social and support networks are unlikely to have ever experienced what you are going through, and this can add to the isolation felt by families”.

These sentiments were echoed many times over by families who participated in the current Queensland consultation process. In the words of another mother with a boy with Duchenne from the Gold coast:

“My son is 8yrs and has not been invited to a birthday party for 3 years. He has not been invited to a playdate or sleep over with any of his peers ever. We have held these activities and not been offered any invitations in return. As a parent I see very little of other people in a social setting. I am either at work, at medical appointments, quickly doing the school run, at a computer dealing with invoices, the NDIS, specialists, physios, school, Plan Managers, support co-ordinators, researching equipment, appointment setting etc. There is very little time for a coffee. It can feel quite isolating at times and very lonely. I struggle now to find common ground to talk to other parents as I am out of practice because we are immersed in being carers rather than parents to our son.”

Save Our Sons Duchenne Foundation Consultation Process:

Save Our Sons Duchenne Foundation was determined to consult as widely as possible with the Duchenne and Becker community across Queensland in the preparation of this submission. Social media posts and newsletter articles were initially distributed to encourage the community’s participation and feedback to the Inquiry. Following this, a series of individual zoom consultations of 30-45-minutes duration were held with parents/carers of boys/young men with Duchenne.

³ McKell Access Economics Institute Report Page 15

Participants including boys/young men with DMD and Becker were also able to email written feedback and responses.

A series of questions were posed to those involved in the consultation, a copy of which appears at **Attachment One** at the conclusion of this submission. These questions attempted to go to those issues we considered most relevant to some of the Terms of Reference (TOR) of the Inquiry.

In addition to this consultation, the SOSDF team held some community meetings in Brisbane in May 2021, with the DMD and BMD community (including young people with the condition). While these meetings preceded the establishment of this particular Inquiry, these meetings confirmed to SOSDF staff, that isolation and loneliness were critical issues amongst community members - with limited opportunities available for quality connection and interaction being articulated by several participants.

Shortly after these meetings, the SOSDF team applied for a Queensland Mental Health Grant to enable SOSDF to organise a further community dinner and self-care workshop in October 2021 for Queensland families grappling with DMD and BMD (A copy of this application is **attached** for the Committee's information).

Finally, and as already highlighted an extensive (and complementary) consultation with the Duchenne and Becker community had already been undertaken by the McKell institute as part of their research on behalf of SOSDF. While this work was across all states, it nonetheless engaged families from across Queensland. An extensive survey targeting the Duchenne and Becker community had been launched on 4 December 2019 and closed on 23 December 2019. ⁴There was a total of 173 responses, a sizeable sample of the estimated population living with Duchenne and

⁴ Mc Kell Report Pages 14/15.

Becker in Australia. 77.05% of this sample were parents of children with Duchenne and Becker and grandparents and siblings made up the rest.

Structure of Save Our Sons Duchenne Foundation submission:

Our submission is structured to highlight those key issues which were identified by our families throughout our consultation process which led to heightened experiences of isolation and loneliness. The submission is not intended to be a comprehensive “catch all” response (or generalisation) and importantly recognises, that variations exist in the experience of families across Queensland (especially for example, in relation to the levels of inclusion in the education system). Responses have been made in good faith and in a concerted attempt to draw attention to gaps and shortcomings in social and community provision. These responses are made in the hope, that positive change and increased funding and attention to the issues of a highly disadvantaged rare disease community, are forthcoming.

Save Our Sons Duchenne Foundation will subsequently make a series of **recommendations** at the conclusion of this response which in large part, will reflect the outcome of our discussions with the Duchenne and Becker community in Queensland.

Finally, at **attachment 2** of this submission we have attached some videos for the Committee to review and consider as they provide invaluable insights into the “lived experience” of those who are suffering from Duchenne and Becker muscular dystrophy.



Terms of Reference:

Following consideration of all the Terms of Reference for the Inquiry, SOSDF determined to concentrate our energies and resources on those Terms of Reference most relevant to our community. In this instance we have chosen to focus primarily on four of the six terms of reference and to concentrate most heavily on those TORs (TOR 2/3) where we received most information and input. Our response to those 4 terms of reference follows:

1) *the nature and extent of the impact of social isolation and loneliness in Queensland, including but not limited to:*

- o identification of and consultation with vulnerable and disadvantaged individuals or groups at significant risk across the life course***
- o the interplay of COVID-19 with this issue***

As already highlighted, social isolation and loneliness are widespread amongst the Duchenne and Becker community in Queensland, which is arguably one of the most disadvantaged groups in the State. Not only are their enormous financial, personal and social costs arising for families with the lived experience of the disease (costs which place an enormous toll on this community's ability to engage in social, leisure and recreational opportunities) but the progressive muscle wasting nature of this disease means that young boys and men suffering from the condition, experience increasing difficulty in engaging with their peers and the broader community -as their physical capacity for engagement and participation, declines over time.

Subsequently, on-line gaming and other web-based interactions with peers often prevails for many, meaning these young boys/men miss out on the robust and more satisfying/nurturing forms of direct personal and social interaction. Says one grandmother of a boy with Duchenne based in Northern Queensland:

"The sole contacts of my grandson are international via the internet".

Notwithstanding that there are an increasing number of boys and young men with DMD and BMD who are achieving remarkable things, (and against huge odds) isolation and loneliness are nonetheless pervasive. Says one young man from Brisbane with Duchenne.

"Loneliness and isolation are huge factors for people with DMD and BMD. Our community experiences higher level of these feelings, especially the older people in the community. Lack of a social circle. As the condition progresses it can be more tiring to go out.....DMD and BMD can limit a person to activities that they can do. Also, places need to be accessible and have accessible toilets etc. Also, a lack of connection or opportunities for experiences. Tiredness can have an effect.

Isolation and loneliness are experienced by the DMD and BMD community (parents/carers and sons) across a range of different contexts from schooling, sport and recreation,

through to social groups, employment and community life. The factors behind this will be explored in more detail in the following term of reference, but suffice to say, parents/carers get too little respite and quality “free time” and generally struggle to find sufficient support networks and peers with whom they can interact, find support and debrief. Boys and young men on the other hand, find too many physical barriers and exclusive cultures still in play. One Queensland mother reported to SOSDF, that her son with Duchenne was 12 years old and had been excluded from school sports days.

“Nothing is offered in 1st year in high school. He just sits on the sidelines and watches others participate. Schools need to step up”.

An NDIS report of note:

⁵“Participants with a Neurodegenerative Condition in NDIS, March 2021” is another significant report for purposes of this Inquiry. This report is produced by the NDIA as part of its annual reporting requirements. ⁶This report highlights amongst many other things, the strong desire of the carers/parents of children and young people with muscular dystrophy to spend more time in paid employment (a critical point of social activity and interaction) and to spend more time with their friends.

⁷This report also highlights the low levels of participation by children/young people with muscular dystrophy involved in a community, cultural or religious group in the past 12 months (approximately 30-38% across all ages). Sadly, the report also reveals that approximately 40% of boys/young men with muscular dystrophy do not have any friends outside of their family or paid staff.

These are clearly all facts worth bearing in mind when considering issues of social isolation and loneliness in Queensland.

⁵ NDIS “Participants with a Neurodegenerative Condition in NDIS” March 2021

⁶ NDIS “Participants with a Neurodegenerative Condition in NDIS” March 2021 Page 74.

⁷ NDIS “Participants with a Neurodegenerative Condition in NDIS” March 2021 Page 69.

Impacts of COVID:

For a community that is already extremely isolated with more limited social options and resources, the impacts of COVID (and specifically lockdowns) have generally varied. Overall, however, COVID has compounded the isolation and loneliness experienced by this community. Boys and young men with DMD and BMD are likely to be more at risk of having more severe symptoms if they contract a COVID-19 infection especially if they have heart or respiratory issues. On that basis, many boys and families have been required to curtail social and recreational activities during the COVID period.

A young man with Duchenne highlighted this problem during our consultation

“People with DMD and BMD are very vulnerable when it comes to COVID. The events that they may have may be too dangerous now”.

Another mother of a young man with Duchenne from Central Queensland highlighted how COVID had really exacerbated the isolation and loneliness experienced by many young men with this condition:

“Yes, many are lonely and have no friends, many only have families as their friends and some will not admit it. They may have people to talk to but they need someone to actually come and hang out with you and spend time with you and this is not happening and Covid is also a huge contribution to this. Firstly, for their safety and secondly people who are normal and do not have a disability or an illness can go out and live life where others are stuck at home and nobody cares for them. As I say they have friends in the same boat, but it is not the same especially when the young men would also like a young lady to be interested and maybe a relationship out of that”.

Snap lockdowns have also been more problematic for families in terms of accessing treating specialists, therapies, carers and medications. Home-schooling has also been particularly challenging especially where a boy may also have a comorbid behavioural disability/learning difficulty such as autism which is common amongst boys with this condition.

As with the wider community, lost travelling opportunities were also a toll of the virus -an issue compounded in the DMD and BMD community because “time is of the essence” (disease

progression, loss of mobility and muscle usage) for these boys/young men with this life limiting condition.

Stated one mother of a Duchenne boy from South-eastern Queensland when asked if COVID had played a role in increasing isolation and loneliness:

“Absolutely-since COVID things have been worse. He missed out on loads of therapy last year which affected his application when applying for NDIS funding, he was given less money, because of course we did not have the opportunity to utilise the funding.

Travel restrictions have meant that our boy could not visit his auntie in New Zealand. Also, time is not on side for these boys, we wanted to take our boy overseas while he could still travel. We booked a trip to Europe which was cancelled indefinitely”.

The inability for carers and other support persons to visit families during COVID lockdowns was another issue increasing a sense of isolation and loneliness amongst the DMD and BMD community.

2) the causes and drivers of social isolation and loneliness, including those unique to Queensland

Our consultation identified many factors resulting in increased isolation and loneliness for the DMD and BMD community in Queensland, some of which appeared to be compounded in the local State context. For example, remote locations, fewer support services than other states etc.

Save Our Sons Duchenne Foundation will just concentrate on a few of the key findings below:

a) Lack of support services: “Connecting the Unconnected”.

The DMD and BMD community consistently highlighted the lack of support services and options available to both parents/carers and young people in Queensland which were dealing with this rare condition.

Where once there appeared to be more services offering regular parent support groups, counselling, camps for young people etc., many families lamented what they claimed was the lack

of current programs and services or a refocussing of service delivery by some organisations - towards more specific, targeted and critical NDIS provision.

These sentiments are captured in the following statement from a Queensland mother of a boy with Duchenne living in a remote part of Queensland:

“Our major city is Brisbane-we have very little in terms of social groups and anything that is run is in Brisbane only -which leaves people in other parts of Queensland isolated.

When we see events that happen in NSW and Victoria such as the walks, BBQs, conferences etc it makes me sad, and we feel left out. My boy doesn't get affected as he can't read and does not see the emails regarding “whats going on in the community” but I do, and I live and breathe Duchenne through my son. He gets very upset about having weak muscles and not being able to take part in sports and things at school. He hates that he is different, and he feels useless.

Perhaps if I had more support -he would feel more connected”

“The lived experience” of DMD and BMD for both parents/carers and the boys/young men places an enormous toll on the mental health and well-being of all involved. Parents/carers typically grieve throughout all different stages/life cycles of the disease -from diagnosis, loss of mobility, schooling and post schooling transitions, through to declining health and death. And all too often, parents/carers are doing this on their own or without sufficient support and backup (especially where marriage and other significant partnerships/relationships have all too often broken down).

Unfortunately, self-care, social/community interaction and quality respite become “luxuries” for many community members meaning that mental health is often compromised - and this despite the incredible resilience, fortitude and strengths displayed by many of these families. The needs for accessible and specialised counselling/psychological services, support groups and opportunities for social connection and capacity building are therefore paramount. Sadly, these remain largely unmet needs in Queensland.

Programs designed to meet the mental health and well-being (personal/social/recreational/health) needs of boys and young men with DMD and BMD are also critical as they contend with the debilitating progressive advance of the disease and the barriers and exclusions which are put in place by mainstream social institutions.



(SOSDF brought some families together at community meetings in Brisbane earlier this year. The feedback we received helped motivate us to participate in this Inquiry)

This is perhaps no more apparent than the lack of opportunities for DMD and BMD boys/young men to participate on camps which was one issue consistently raised by this community. Camps were seen as providing key opportunities for participants to experience new surrounds, directly interact with peers and build ongoing social relationships. They were also seen as invaluable skill development opportunities with participants pushed to learn and “master” a range of new activities. Camps were also seen as opportunities for parents/carers to have some much needed respite from their onerous carer responsibilities.

As exclusion from school camps and activities appears to be an ongoing reality for many DMD and BMD boys, camps and activities run by the non-government/charity sector become more critical. Yet unfortunately, there appears to be a dearth of options available. Furthermore, funding for participation on camps becomes an issue when local options are few and far between. Save Our Sons Duchenne Foundation staff are looking for opportunities to fill some of the isolation and gaps in community connectedness, however COVID has severely impacted on our ability to hold large fundraising events and we have no government funding to offer scholarships into services like camps in other states.

One Queensland mother we spoke to took the extraordinary step of sending her son on a camp in NSW and utilising core NDIS funding for this purpose:

“The cost of attending this camp was huge but we wanted our son to have the chance to do some activities that he cannot usually do such as abseiling as the camp had adapted equipment and adequate support to enable this. To begin with I had to apply for NDIS funding the previous year in advance. This came at a cost too as the NDIS scheme did not give us much extra funding towards it, so we had to pool it from other areas in our NDIS plan. In addition my husband and I both had to take leave, and then of course there was the expense of travel and accommodation. In short, it ended up being an expensive do”.

Another mother of a boy with Duchenne bemoaned the fact that:

“My boy is 12 and we have never encountered a camp”

Lack of community self-organising:

Finally, the lack of a sense of community/connection amongst DMD and BMD families in Queensland was highlighted as a major factor in loneliness and isolation (partly as the outcome of a lack of support services). One family went to great lengths to discuss the lack of self-organising that occurred amongst Queensland families in great contrast to what they had experienced previously in Victoria where it was not uncommon, for 40-50 community members to regularly get together, share information and experiences and catch-up on a social level. These catchups being so vital for mental health and connection. This is not happening in Queensland.

Said one dad with a Duchenne boy who had relocated from Victoria to Queensland:

“The community is not strong up here. It is much stronger in other states. No-one is bringing the community together to be strong, no-one is connecting people especially when children are diagnosed. Social media networks are not strong up here....the feeling that you are not alone is really important. It’s harder to know what you can do up here. In Victoria, information is shared”.

b) Inconsistencies across the Education system: “It’s largely about the Principal”

One of the most frequently cited reasons for the isolation and loneliness experienced by boys/young people with DMD and BMD was the exclusion some experienced in the Queensland education system.

While some parents were full of praise for the efforts of schools to ensure schools were inclusive and provided accessible facilities, others were scathing and highly critical arguing that schools did little to educate staff and students about disabilities:

Said one mother of a Duchenne boy from North Brisbane.

“Kids at school are not being educated about difference. It’s all about education and making disability mainstream. If people have knowledge, then maybe kids won’t point and giggle when my son runs. We need to start with the kids and work our way up. At the moment schools are simply not stepping up”.

Another mother from central Queensland with a boy with Duchenne relayed this heartbreaking story of her son’s experiences at school:

“Imagine being able to fly and then losing your wings? That is what it is like for these boys. They watch their peers progress and grow, strengthen their skills and live their dreams. They watch their friends flourish and know they never will. My son had friends at school in prep, year one and two. They have ditched him in the playground now to play football etc, so he is left with the girls now. The boys help him in the classroom but out on the playground, they want to run around and not look after him”.

And this from a mother of a Duchenne boy from the Gold Coast:

“I think a focussed program on inclusion by Education Queensland that encourages staff AND students about disability inclusion is needed. Proper courses presented by disabled members of the community. Too many prominent people in my son’s life do not have a fundamental grasp of what inclusion means and only put in a basic level of effort in catering to the disability sector”.

In late 2020, SOSDF prepared a collective submission to the ⁸Federal Education Department’s Review of the *Disability Standards in Education 2020*. A copy of this submission is **attached** for the Committee’s attention. Many of the issues we identified through that consultation process are applicable to the Queensland context – in short, factors identified as part of this current SOSDF consultation process are not unique to Queensland but appear to be prevalent across our primary and secondary school systems in all state jurisdictions. We note for example, some of the common threads between the Queensland Inquiry consultation and the broader education consultation. Namely, the lack of knowledge/awareness of DMD and BMD in the various education systems and the critical role that School Principals can play in determining how inclusive a school culture can be - and the prioritisation which is given to reasonable adjustments, learning support and wheelchair accessible facilities.

On the flip side, one dad with a boy with Duchenne from Brisbane could not speak highly enough of the efforts which were made by the School Principal in making his son’s school inclusive and accessible:

“Its 100% the Principal. The school is very inclusive. All buses are wheelchair friendly, we have wheelchair accessible toilets and ramps and we even have wheelchair sports days”.

c) The great outdoor Queensland culture: “Beautiful One Day, Perfect the Next”

As highlighted previously, Queensland’s emphasis on an outdoor lifestyle and beach activity, is particularly challenging and alienating for the DMD/BMD community where physical disability can be so restrictive. This is particularly so when many basic facilities and equipment are missing - wheelchair ramps, beach wheelchairs, sporting options and clubs with adaptive equipment etc.

Says one dad with a son with Duchenne from Brisbane:

⁸ [2020 Review of the Disability Standards for Education 2005 - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](https://www.dese.gov.au/2020-review-of-the-disability-standards-for-education-2005)

“Its all about getting outdoors, so it makes them feel like they can't participate in the community”

Save Our Sons Duchenne Foundation notes as an example, the lack of inclusive activities listed in the holiday guide below produced by the City of the Gold Coast council.

<https://new.goldcoast.qld.gov.au/Things-to-do/Active-Healthy-program/Active-Healthy-holiday-programs>.

On a positive note, this council does appear to be making some steps forward in ensuring greater accessibility to beaches (Beach Access Program) and other facilities for people in wheelchairs. For example, through the provision of beach wheelchairs and beach matting, mobility maps, mobility equipment hire and recharge points.

It is worth noting however, that many young men with Duchenne and Becker have no upper arm strength and cannot self-propel. On that basis they require power wheelchairs for independent mobility -these are not readily available for hire and nor can they manage some of the beach and other outdoor terrains in question.

If some outdoor activities are not negotiable for these families, then additional efforts need to be made by political, community and business leaders to ensure there are other options and alternatives (rather than home based internet activity) which are fully inclusive and accessible to this community.

d) Transport Issues: “Accentuated in the BIG Queensland context”.

Transportation issues are compounded in Queensland because of the remoteness of some families and the vast distances involved in travelling to essential services such as the Queensland Children’s hospital in Brisbane -where neuromuscular clinic services are available.

Despite most airlines and airports having disability action plans, wheelchair accessibility on regional and domestic airlines remains problematic and a major hurdle to be navigated by families needing to travel large distances and in reasonable timeframes. SOSDF has heard several stories of wheelchair damages incurred and/or other problems encountered at airports for those travelling in wheelchairs. This of course works to reinforce the isolation and loneliness felt by many families as travel becomes a major (and costly) exercise in itself.

Wheelchair modifications to vehicles are essential for many families especially in remote areas with poor local transport infrastructure and options. Yet such modifications have proven to be extremely problematic and costly for some families.

As explained by one mother of two Duchenne boys from North Queensland:

“Vehicle modification is a big issue. It took me a year of fundraising to raise enough money for the vehicle. We went months without mobility while buying the new car”.

Other families talked about the ongoing bureaucratic delays they experienced with NDIS in obtaining sufficient funding to modify their vehicle. Such delays simply isolate families who may be dependent on such vehicles to undertake daily activities (let alone go on longer trips and holidays).

Save our Dons Duchenne Foundation heard little comment about bus and train accessibility issues from our community. However, after reviewing some of the Queensland Government’s travel information websites we did note the following (including several very positive developments);
-⁹some but not all long-distance trains are wheelchair accessible;

⁹ <https://www.qld.gov.au/disability/out-and-about/travel-transport/rail-travel>

-all new trains and train stations and buses/bus stops must comply with [Disability standards for accessible public transport](#) and upgrades to new stops are currently underway;

-an excellent station access guide is available at <https://www.queenslandrail.com.au/forcustomers/access/station-access-guide> which suggests most city and suburban railway stations are wheelchair accessible with accessible toilet and other facilities available ((although there remain some notable exceptions);

-most buses on the Translink network have low floors or ramp systems. Stations along busways—roads dedicated to buses—have lifts, ramps and pathways;

-it is less clear about wheelchair accessibility on private buses or accessibility with bus operators in regional Queensland who are outside the Translink area of Southeast Queensland.

e) Lack of community awareness and knowledge of Duchenne: “There is none”.

The last factor SOSDF will highlight in relation to the issue of social isolation and loneliness is the lack of knowledge and community awareness of Duchenne and Becker muscular dystrophy. Not uniquely a Queensland factor, it is nonetheless pervasive in the broader community and impacts all interactions between the DMD and BMD community with educational, health, recreation, cultural/arts and social institutions and providers.

This lack of community awareness is very isolating for community members who are forced to advocate, educate and explain at all levels to ensure their child receives the equivalent access to social goods and services as the able bodied. This also translates to friendships and other relations and highlights again, the need for support groups and other connections between people who share the lived experience of this disease.

As explained by one mother of a boy with Duchenne:

“Friends in the community just don’t get it. We are all so isolated, and unless we come across people with same issues on Facebook, we just miss out”.

Greater community awareness of rare diseases such as Duchenne and Becker muscular dystrophy will facilitate a more inclusive and embracing culture and subsequently ensure, that much of the social isolation and loneliness experienced by this community is broken down.

3) the protective factors known to mitigate social isolation and loneliness

“Providing services and social groups for people with DMD and BMD. Having things to do and meeting new people. Finding meetups and going to events. Having a social circle. Shifting people’s perspective towards disability. Need to have a more inclusive society....programs like “Just Like You” by Variety Children’s charity can be helpful, especially in schools”.

(A young Queensland man with Duchenne).

As should be clear from this submission the key protective factors which SOSDF believes will mitigate social isolation and loneliness for the Duchenne and Becker community will include but not be limited to:

- more opportunities for connection with other people who share the “lived experience” of DMD and BMD;
- more opportunities for greater connection with the broader community in relation to social/recreational/leisure activities and opportunities;
- public investment in services and infrastructure which facilitates greater levels of involvement and interaction of the DMD and BMD community in social, cultural and community life;
- provision of accessible and specialised services which are delivering mental health and well-being support and which are informed by the “lived experience” of rare diseases such as Duchenne and Becker muscular dystrophy;
- a more inclusive culture which embraces and engages with young people with DMD/BMD throughout all stages and aspects of their lives – in schooling, employment, recreation/social, health etc;

-community infrastructure and sporting/recreational/social organisation which are fully accessible and inclusive of the DMD and BMD community;

-greater public awareness and understanding of rare disease conditions such as DMD and BMD and the need to embrace this community in all aspects of community and social life;

-public acknowledgement and recognition of the resilience, fortitude and strengths of this community and the need for society to learn from, value and gain knowledge/insights from the lived experiences of those members of the community dealing with DMD and BMD;

-removing access barriers that may still exist on aircraft and our road, rail and bus systems and networks; and

-streamlining and making more cost efficient, the process for vehicle modifications to enable wheelchair accessibility and day to day mobility for families.



1) how current investment by the Queensland Government, other levels of government, the non-government, corporate and other sectors may be leveraged to prevent, mitigate and address the drivers and impacts of social isolation and loneliness across Queensland, including:

services and programs such as health and mental health, transport, housing, education, employment and training, sport and recreation, community services and facilities, digital inclusion, volunteering, the arts and culture, community

Save Our Sons Duchenne Foundation seeks only to make some very brief comments in relation to this term of reference as much of the ground has already been covered in the above. Simply, we say that more investment needs to be leveraged at all levels of government and the private sectors to ensure that more services and programs (such as those detailed in the TOR) are delivered and provided in such a way, as to ensure greater inclusion and consideration of the needs of rare disease communities such as the DMD and BMD community.

Save Our Sons Duchenne Foundation believes the Queensland State Government can play a key role in coordinating the different tiers of Government in this effort while providing the brokerage that may be necessary to deliver a range projects and programs which are designed to mitigate and address the drivers of social isolation and loneliness. For example, mental health and well-being initiatives which are cognisant of and adapted to the various phases of the Duchenne and Becker disease life cycle, public awareness campaigns which raise awareness of inclusion issues (and which are underpinned by a philosophy that people are only disabled to the extent our society excludes them), public works programs which increase wheelchair accessibility and facilities etc.

As providers of many services and programs, the State Government is ideally placed to ensure that its agencies are delivering services with inclusion issues, policies and practices centre-stage. These agencies are also best placed to consult with disadvantaged rare disease communities and their representative organisations about the types of programs and infrastructure which should be delivered to ensure that issues of isolation and social exclusion are mitigated. The Committee should note that SOSDF is prepared to help facilitate such a consultation process with the Queensland DMD and BMD community.

Finally, audits of existing infrastructure, programs and projects should also be undertaken to ensure inclusion and accessibility issues have been adequately addressed. With the hosting of an upcoming Olympic/Paralympic games it becomes incumbent on the Queensland Government to undertake such activity and to leverage investment and commitment from all Government levels and the private sector towards this effort.

Conclusion:

Although this Inquiry is broadly based and targets the entire community of Queensland, Save Our Sons Duchenne Foundation nonetheless believes it provides an invaluable and unique opportunity to constructively progress some concerns which have been present for Duchenne and Becker families living in Queensland.

Save Our Sons Duchenne Foundation is therefore extremely thankful that this Inquiry has been established by Members of the Queensland parliament with cross-party support. It demonstrates an important political consensus around the need to move the agenda forward in relation to ensuring issues of social isolation and loneliness are addressed and strategies implemented. This submission has been written in good faith and as an attempt to make an important contribution to this process. Save Our Sons Duchenne Foundation has endeavored to raise those issues as fairly and as accurately as they were articulated to us by members of the Duchenne and Becker community.

Save Our Sons Duchenne Foundation makes no apology for attempting to capitalise on the bi-partisan political momentum which has now been built up in relation to the issues which are the subject of the Inquiry. The general happiness and well-being of our community are much too important for us not to actively participate in the important work of this Committee.

Our organisation, along with the wider Duchenne and Becker community, would therefore welcome any further opportunities (e.g., public hearings) to participate and provide further feedback to the Committee.

Save Our Sons Duchenne Foundation conclude this submission, with the following heartfelt statement from a Queensland mother of a boy with Duchenne. We believe this statement neatly summarises the tasks ahead for all parties who are concerned to address issues of social isolation and loneliness:

"I think those boys AND girls living with DMD or BMD experience much greater levels of loneliness and isolation than their peers. In mainstream school there desperately needs to be a greater focus on inclusion and belonging for students with a physical disability. Many areas of life are set up for able bodied people and do not factor in the challenges people with muscular

dystrophy face every day trying to fit in. In society there is not enough inclusion being displayed for people with a disability. That seriously needs to improve”.



(Launch of the FIPFA Powerchair Football World Cup in Sydney 29/4/21.
Powerchair football is a very popular sport amongst the DMD community)

RECOMMENDATIONS:

1. That the Queensland Government investigate and deliver funding for a suite of programs (including programs addressing mental health, well-being and respite) which are targeting rare disease communities such as the Duchenne and Becker muscular dystrophy community in Queensland;
2. That any new programs and services which are targeting rare disease communities such as DMD and BMD be designed to improve opportunities for connection and social interaction between families and young boys/young people along with providing opportunities to participate in skill development and new experiences.
3. That the provision of social and recreational opportunities for boys/young people with DMD and BMD (for e.g., camps) be explored by the Queensland Government in consultation with the Duchenne and Becker community;
4. That further reviews/audits of inclusion practices and policies within the Queensland Education Department be undertaken to ensure consistency and inclusion is practiced and celebrated at all schooling levels and across the entire education system. Further, that these inclusion practices are consistent with the recommendations of the Federal Government's review of the *Disability Standards in Education 2020*.
5. That continuing work (including audits) be undertaken to ensure accessibility of all transport systems (including air, road, rail, buses and ferries) across the Queensland transport system and networks;
6. That potential barriers to inclusion of rare disease communities such as DMD and BMD, in sporting, recreation, employment and leisure facilities/clubs/bars/gyms etc be investigated

and addressed by the Queensland Government -in consultation with the disability and rare disease sector;

7. That a specific consultation be organised between Queensland Government agencies and the Duchenne and Becker muscular community to investigate and develop strategies to address issues of social isolation and loneliness identified by this community in Queensland;
8. That the 2032 Brisbane Olympic/Paralympic games be recognised (and utilised) as an invaluable opportunity by the Queensland Government to address any impediments and barriers (e.g., physical infrastructure) to the full participation of people with disabilities and rare diseases in social and community life.
9. That the Queensland Government embed within the building/construction works for the upcoming Olympic/Paralympic games, improvements to infrastructures and facilities to ensure maximum accessibility for people with disabilities.
10. That the Queensland Government commit to regularly evaluate and report back to the broader and rare disease communities, the outcomes arising from this Inquiry.



REFERENCES:

- 1) McKell Institute “Living with Duchenne and Becker in Australia: Supporting Families Waiting for a Cure” Angela Jackson/Equity Economics



Tony Zappia MP; Emma McBride MP; David Smith MP; Hon Warren Snowdon MP; Chris Hayes MP; Hon Chris Bowen MP; Peta Murphy MP; Dr Mike Freeland MP; Hon Tony Burke MP

(Official Launch of the McKell Report September 2020).

- 2) NDIS “Participants with a Neurogenerative Condition in NDIS” March 2021

- 3) <https://new.goldcoast.qld.gov.au/Things-to-do/Active-Healthy-program/Active-Healthy-holiday-programs>.
- 4) <https://www.qld.gov.au/disability/out-and-about/travel-transport/rail-travel>
- 5) [2020 Review of the Disability Standards for Education 2005 - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](#)
- 6) <https://rarediseases.org/rare-diseases/duchenne-muscular-dystrophy>



ATTACHMENT ONE:

Consultation Questions:

Queensland Parliamentary Inquiry into Isolation and Loneliness in Queensland

- 1) Do you think loneliness and isolation are big factors for the Duchenne (DMD) and Becker (BMD) community in Queensland and if so, do you think the DMD and BMD community experiences higher levels of loneliness and isolation than the rest of the community? Why?

- 2) What do you believe are the factors which most contribute to isolation and loneliness experienced by parents/carers of those young boys and men with DMD or BMD?

- 3) Is there anything unique to Queensland which you believe contributes to issues of loneliness and isolation for DMD and BMD community?

- 4) Do you believe young boys and men with DMD and/or BMD experience greater levels of loneliness and isolation than their peers? What are the factors you see as being most important here?

- 5) From your experience what are the most important factors to prevent social isolation and loneliness being experienced by members of the DMD and BMD community?

- 6) Has COVID played a role in increasing isolation and loneliness amongst members of the DMD and BMD community in Queensland? How?

- 7) What suggestions/recommendations do you have for the Queensland Government to address issues of isolation and loneliness for the DMD and BMD community?

- 8) Do you have any suggestions on specific services, facilities and programs the Queensland Government could fund or enhance to address loneliness and isolation for DMD and BMD families in Queensland?

ATTACHMENT TWO

1) **Save Our Sons Duchenne Foundation YouTube Documentary**

This 8-minute video is available on YouTube and produced by Save our Sons Duchenne Foundation which gives a brief overview of Duchenne muscular dystrophy and the work of Save Our Sons in finding a cure to this condition.

<https://www.youtube.com/watch?v=GcI7od9fqxs>

2) **6 of 9 Documentary**



The following 45-minute documentary was made as a lasting gift for his family by Martin Dix a Melbourne born and raised film maker residing in Los Angeles. It is the story of Martin's brother Kieran who suffered from Duchenne muscular dystrophy and passed away some years ago. When COVID 19 struck in the US, Martin finally found the opportunity to edit over 40 hours of archival footage of his brother Kieran's life – footage which had been left stored away for many years. What he finally produced is a moving documentary which documents both the lived experience of Duchenne for those who suffer directly from it, but also the huge emotional and personal impacts for those who care and love someone with the disease – in this case, Martin's seven other brothers and his mum and dad. Save Our Sons Duchenne Foundation feels honoured that Martin wanted our organisation to use this film as part of our advocacy work and on that basis, we are privileged to be sharing this with members the Community Support and Services Committee.

https://vimeo.com/427928501?fbclid=IwAR10sETVXNJLt7on1Og2FIDjo8GFKIbIB1ahyxuSrMbt_9y2-X9WIjxgR9s

Lance Dale

Advocacy Officer

Save Our Sons Duchenne Foundation

10 August 2021.

