20 February 2021

Save our Sons Submission: National Disability Insurance Scheme: Consultation Paper: "*Access and Eligibility Policy with Independent Assessments:*"

Introduction:

The Save Our Sons Duchenne Foundation (SOSDF) thanks the NDIA for an opportunity to make comment in relation to the consultation paper "*Access and Eligibility Policy with Independent Assessments".*

These comments are made "without prejudice" to the position we are making in relation to our broader and more comprehensive submission to the Federal Joint Standing Committee on the National Insurance Disability Scheme Inquiry into the proposed use of Independent Assessors. That submission will raise a number of objections and concerns to the introduction of Independent Assessors (IAs) and will draw heavily on the input of the Duchenne (DMD) and Becker (BMD) muscular dystrophy community in Australia.

This submission on the other hand, while largely informed by the views of the community we represent, is written on the basis that the proposal for IAs will proceed in some form or the other. The submission is therefore drafted in a pragmatic fashion and within the parameters of the consultation paper only. The submission will only deal with those questions which have been posed by the NDIA in the consultation document.

Who We Are?

The Save our Sons Duchenne Foundation is the peak body representing the Duchenne and Becker muscular dystrophy community in Australia. The organisation has been in existence for over 12 years and is instrumental in funding clinical trials, leading research projects and a nurse's program at several children's hospitals across Australia. In addition, the organisation has an established telehealth nursing service, develops a range of community programs/resources and is actively undertaking systemic advocacy work on behalf of the community we are representing. SOSDF is also responsible for

establishing a range of innovative fundraising and marketing events which aim to not only raise money for important community initiatives and research, but also, to raise community awareness of the Duchenne and Becker conditions.

It would be an understatement to argue that the support provided by NDIS is critical to the personal health and well-being of young people with Duchenne and Becker and their families. Without this support, these families who are already overburdened meeting the social and financial costs of this disease, simply could not cope. And nor could the young boys and men suffering this terrible condition be able to participate more fully in the social and community life of the community - and have their complex and ever-changing personal and health care needs properly attended to.

On that basis it is critically important that the NDIA ensure that any implementation of Independent Assessors as proposed in the consultation paper is done appropriately and is fully informed by the issues and complexities of rare disease conditions such as Duchenne and Becker muscular dystrophy. Further, that any implementation occurs in full consultation with the DMD and BMD communities and those organisations established to represent them.

Consultation Questions as posed in the Consultation Paper:

Following are the SOSDF responses to the specific questions posed in the Access and Eligibility consultation paper.

Learning About the NDIS

1) ***What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?***

Information will be required on:

- the relationship between the independent assessment process and the final determination on NDIS eligibility and funding;

- the background, qualifications and the role of Independent Assessor;

- rights and avenues to appeal the outcome of an Independent Assessment;

- the process for the actual Independent Assessment -how will this be organised, over what sort of timeframe and what sort of additional information/reports the Independent Assessor will consider when determining functional capacity?

- the basis of the Assessment and the assessment tools (and their appropriateness) which will be utilised to carry out the Independent Assessment;

- whether support people or other health specialists can be present during the Independent Assessment interview and provide input; and

- the timeframe between the Assessment and the determination on NDIS/eligibility and funding.

This information should be provided well ahead of the actual assessment to provide individuals and families with an opportunity to clarify aspects of the assessment process before they meet with an Independent Assessor. Those organisations who represent rare disease communities such as DMD and BMD should be provided with full briefings and resources by the NDIA so that assistance/advice and information can be provided to our community members if required.

Information should be available on-line and in hard copy and published in key community languages.

Accessing the NDIS.

2. ***What should we consider in removing the access lists?***

Reviewing the old system of lists, SOSDF could assume that young boys and men with DMD and BMD would be largely on the old list A, meaning they were more likely to be fast-tracked entry to the NDIS because of the severity of their disability. However, given there is such a poor understanding of the complexities of the DMD and BMD condition and its progressive nature, it may well be that many boys and young men were not on this list but were on the lists B-D.

Access lists may have given some priority to DMD and BMD (a big unknown) in the past, so we are concerned that unless these conditions are fully understood and appreciated by the NDIA (with the removal of the lists), then several boys and young men may be disadvantaged in accessing the appropriate levels of NDIS support.

While SOSDF believes that the removal of lists may help to equalise access to all NDIS users and applicants to NDIS funding, we nonetheless believe that DMD and BMD are such, that those suffering from it **should not** have to jump through assessment hoops in order to determine functional capacities -and the levels of assistance required from NDIS.

3. ***How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent of life long?***

Unfortunately, there is no cure for DMD and BMD. They are life long and permanent conditions and in the case of DMD, result in the progressive extinguishment of all muscle function and sadly, to an untimely and premature death. The best treatments to date have simply stabilised and slowed down the decline in muscle function and the loss of mobility.

There should never be any doubts therefore about the need for these young boys, young men and their families to have ready access to the very best of NDIS funding support.

As many parents/carers from the DMD and BMD community highlighted, the utility of an Independent Assessment which will only ever grab a snapshot of a particular boy/young man's functional capacity at a particular moment in time, is therefore highly questionable especially when that functional capacity can simply change and deteriorate overnight or within a matter of hours.

Explains Deb a mother of a Duchenne boy from Northern NSW:

"We (parents/carers) always look at what's going to be the worse day.
I'm concerned that this could all be about the timing and what happens on the day of the Independent Assessment. Health care professionals know more and take into account the degenerative nature of the condition".

The need for evidence requirements in relation to Duchenne and Becker muscular dystrophy should subsequently be minimized given the gravity of these conditions. Treating specialists and health professionals who have formed relationships with the DMD and Becker families (and who typically appreciate the complexities of the condition) should continue to be the primary source of evidence required by the NDIS in making any determinations in relation to NDIS eligibility and funding.

Our position is perhaps best summed by Sally a mother of a boy with Duchenne from country NSW;

"It would be beneficial to not have to continually "prove" your disability, provided there is a full understanding of the progressive and sometimes unpredictable nature of the disease (things can plateau for a time, or they can change quite suddenly) Again it is about the level of skill and understanding of the assessor. If it is truly independent, they should be pushing for the very best plan for the client not the NDIS".

And again, this from Alison another mother with a boy with Duchenne from country NSW;

"There is absolutely nothing to prove if you have Duchenne".

4. ***How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?***

It is unclear as to why the NDIA would be wanting to do this other than to cost shift on to other (health funding) sources.

While DMD and BMD are unquestionably health conditions arising from a defective dystrophin gene, they are primarily manifest in a range of disabilities (physical and sometimes intellectual) which impair the quality of life of all those who suffer from it. Further, there are huge financial and social costs on those who care for those with DMD and BMD. It therefore becomes an exercise in futility trying to unpack any distinction between disabilities and chronic, acute or palliative health conditions. They are all interrelated and irrespective, funding support and assistance (and lots of it) are required for these boys, young men and their families.

Undertaking an independent assessment

5. What are the traits and skills that you most want in an assessor?

Our community when consulted over this issue (for both the current Federal Inquiry and the NDIA consultation papers) had much to say in relation to this issue. There was much concern that assessors would have no detailed knowledge, understanding or experience of complex conditions such as DMD and BMD. This in contrast to the health specialists they may currently utilising and with whom they may have long standing relations:

One 31-year-old man living with Duchenne told us;

"I am concerned that the assessors will not have a medical background or experience dealing with complex disabilities and needs. My specialists have decades of experience with people who have similar needs to me, something I am sure the assessors will not have".

Further, there were concerns that the assessor would simply overlook key factors and be unable to fully appreciate the circumstances and specific intricacies of this condition.

As Linda a mother of a Duchenne boy from Queensland explained:

"It is a condition that affects all parts of the body and you have such a multidisciplinary team looking after them. An Independent Assessor just can't do this"

There were also several strongly held views that these assessors would simply be administering a one size fits all, "tick a box" exercise in relation to the assessment process and would have no real empathy (or trusting relationship) with the boys and young men.

Finally, concerns have been raised as to the backgrounds, qualifications and health expertise of the Independent Assessors and whether they were simply being utilised as a cost saving measure. As one mother of a boy with Duchenne quipped:

"Are you helping me or just saving money".

Our community have subsequently made recommendations that any Independent Assessors be trained and qualified in conditions such as DMD and BMD and work closely with organisations who currently represent this community. Furthermore, that families should have some choice as to what Independent Assessor to utilise rather than this simply being determined by the NDIA.

***6.* What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?**

The assessment should be organised and negotiated at a place of the DMD/BMD family/young person choosing. The method and duration of any assessment should also be negotiated between the IA and the family/young person prior to the actual assessment.

Families and young people should be given the opportunity to have a support person or chosen health professional at the assessment meeting.

A major concern of the DMD and BMD community was the duration of the assessment meeting and the difficulty in already busy and frenetic schedules of having time available for yet another meeting relating to the care of their son/s. There was also concern that some boys would not have the attention span for a 3–4-hour meeting with an assessor (if direct involvement required) and further, they many would simply indicate they can achieve what a particular assessment tool is evaluating (administered by a complete stranger) out of self pride. Who for example wants to tell a complete stranger that they are unable to do many of the things (e.g., tie own shoelaces) that many of us simply take for granted?

On the flip side of this, was the widely held belief that a proper assessment of functional capacity could not occur in one 3–4-hour session (as had been suggested for duration of assessment interview) and that no assessment could capture the "ebbs and flows" and daily fluctuations of Duchenne and Becker.

7. **How can we ensure independent assessments are delivered in a way that promotes cultural safety and inclusion?**

SOSDF provides the following few suggestions in relation to this issue:

- ensuring that an Independent Assessment is conducted in a way which is culturally appropriate – for example, information is provided in community languages, an interpreter of someone from a particular cultural background is available to provide support and assistance throughout the assessment process, the Independent Assessor has cultural awareness and training; ethnic, and Indigenous organisations are consulted and involved in the delivery of the assessment process;

- ensuring the families and boys with DMD and BMD are **empowered and consulted** throughout the entire assessment process -both before and after the formal assessment. That all aspects of the assessment process are negotiated with families and the boys/young men to determine how best to undertake and implement the assessment process and to reach any funding determinations that follow;

- families and boys/young men should have the right to make a choice of the particular IA to undertake the assessment process - this should not be something which is simply determined by the NDIA;

- that an assessment process involving a boy/young man with Duchenne or Becker muscular dystrophy must be heavily informed/guided by the reports/input of other health and treating specialists/professionals who already have an ongoing relationship with the family and young person;

- the assessment tools proposed should be subject to review and evaluation by the DMD and BMD community; and

- the appeals process in relation to an Independent Assessment must be strengthened to ensure the most appropriate outcomes are delivered to families and young people struggling with the DMD and BMD condition.

Exemptions:

8. What are the limited circumstances which may lead to a person not needing to complete the independent assessment?

As previously foreshadowed, SOSDF would maintain that DMD and BMD are such that Independent Assessments should not be necessary (this would also be the same for many other rare disease communities). It should suffice that the existing practices involving the submission of reports and advice from health professionals working with the DMD/BMD family, are all that are necessary for NDIS support and assistance.

While DMD and BMD do progress differently in different individuals, the need for NDIS support and assistance is beyond question and should therefore be automatically available-with needs, equipment requirements, additional care and support already factored into existing and future funding equations.

As already stated, where an Independent Assessment is deemed necessary, then families and young people should have the choice of Independent Assessor and a pool of assessors trained in rare disease conditions should be made available. And to confirm again, any such process must be guided and informed by the health professionals already working with these families and young people.

Quality Assurance

9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

First and foremost, a rigorous and accessible appeals process should be available for families and young people to appeal assessment processes which they believe have not been run fairly, nor with empathy and full understanding of the DMD and BMD condition. The current rights of appeals do not go to the Independent Assessment stage but are further "downstream" in the process and can often involve lengthy tribunal proceedings – which can be extremely stressful, and are personally and financially costly. They largely remain as a disincentive for NDIS users to take action over unfair or questionable outcomes.

It is clear from all of the NDIA consultation papers that much will turn on the Independent Assessment outcome. Subsequently, these outcomes must be appealable and/or subject to review and re-assessment.

Regular reviews and consultation should be established between the NDIA and families dealing with DMD, BMD and other forms of rare disease – to ensure the quality of independent assessments are monitored. Reference groups/steering committees involving representatives from the rare diseases sector (including DMD and BMD) should be established to help ensure quality assurance.

An Independent Assessment charter/code of conduct should also be developed which is subject to consultation with NDIS users and which provides the framework and parameters under which Independent Assessors are to operate and the professional standards which they are to meet.

Communications and accessibility of information

10. ***How should we provide the assessment results to the person applying for the NDIS?***

Consistent with the above, results should be provided in an accessible, transparent and easily understood fashion. The rationale for reaching particular results must be made clear to the NDIS user.

Results should be available well before NDIS funding eligibility and determinations are made – to enable results to be appealed, challenged or changed where necessary.

Independent Assessors should be available to meet with NDIS applicants and users (and any health supports) to explain and clarify assessment outcomes.

Conclusion:

As highlighted earlier, this submission has been made on the basis that the proposal for Independent Assessors will be implemented in some form. Our comments are therefore made in "good faith" and with our community concerns front and centre of this discussion.

This submission forms part of a much broader response from SOSDF in relation to the issue of Independent Assessors and should be read in conjunction with our collective response to the Federal Joint Standing Committee Inquiry into the proposed used of Independent Assessors. This submission will be prepared in coming weeks.

SOSDF staff and community are ready and more than willing to participate further in consultation on this Independent Assessor issue and would welcome any further opportunities for comment.

We are available to be contacted by email on lance@saveoursons.org.au or by phone 0466899587.

Thanking you for your attention to this submission.

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