24 August 2021

**Save our Sons Duchenne Foundation Submission: National Disability Insurance Scheme: Consultation Paper: “*Supporting You to Make Your Own Decisions”.***

**Introduction:**

The Save Our Sons Duchenne Foundation (SOSDF) thanks the NDIA for an opportunity to provide some feedback in relation to the consultation paper “*Supporting You to Make Your Own Decisions”.*

This submission has been made following consultation with some families from the Duchenne and Becker muscular dystrophy community. We will be limiting our responses to just a few of questions which are posed in the consultation paper.

**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, cutting edge research projects and a neuromuscular 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.

**Broad comment on the paper:**

It would be a misapprehension to argue that the support provided by NDIS is not critical to the personal health and well-being of young people with Duchenne (DMD) and Becker (BMD) 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. The young boys and men suffering this terrible condition would not be able to participate in the social and community life of the community - nor have their complex, deteriorating and ever-changing personal and health care needs attended to properly.

On that basis, it is critical that the young people/men and their families from the Duchenne and Becker community participate in the NDIS (and wider) decision-making processes - this will require facilitation to maximise their input. Moreover, that NDIS decisions impacting their lives reflect the input, the needs and the aspirations of this unique and special community.

Save Our Sons Duchenne Foundation therefore welcomes the current endeavours of the NDIA to engage the disability and rare diseases sector in consultation around decision-making.

Save Our Sons Duchenne Foundation supports the general “thrust” and the vision promoted by this consultation paper and the need to develop a decision-making policy framework. In saying that, this is well overdue given the size and breadth of the scheme and the fact that NDIS has now been in play for some time.

The overall commitment of the NDIA (as expressed on page 3) to comply with legislative and human rights obligations such as those enshrined in article 3 of the *United Nations Convention on the Rights of People with a Disability* is also welcomed.

Furthermore, we support the principles which have been detailed at page 9 of the paper and especially those principles such as the one detailed below

*Every person, without exception, has the right to make decisions (or contribute to decisions) about things that affect them.*

**Consultation Questions as posed in the Consultation Paper:**

Following are the SOSDF responses to some of the specific questions posed in the consultation paper.

1. **How can we help people with disability to make decisions for themselves?**

One key to enhancing the decision-making of NDIS users is by ensuring that the NDIA is more responsive to the input provided by NDIS users and their families in the first instance. Too often SOSDF has heard concerns/complaints from our community about the unresponsive nature of the NDIA or the ongoing protracted delays in receiving responses to issues which have been raised in good faith. Theses issues were highlighted in the landmark McKell Institute Report “*Living with Duchenne and Becker in Australia*: *Supporting Families Waiting for a Cure*” (**attached**) which was commissioned by SOSDF in 2020, and in the 2019 Tune Review of the NDIS.

If NDIA seeks to help people with a disability make decisions for themselves, then rare disease communities such as ours, need to see more timely responses and clear outcomes resulting from their input. Our community and NDIS users more broadly, need to know (and perceive) that their input is valued and that their involvement is not just tokenistic, a “tick a box” exercise or simply determined by cost considerations.

Save Our Sons Duchenne Foundation was therefore pleased to learn at a recent NDIA consultation, that the NDIA will be developing **a participant charter** -something which appears long overdue.

On a practical level, there are several measures which could be implemented to promote NDIS users making decisions. Some are suggested below:

-establishing more trust between the NDIS user/family and the NDIA (a participant charter would certainly help in this regard);

-training (workshops, seminars) of NDIS user and families in decision-making, self advocacy, building of self-esteem/confidence etc. as this will have a big bearing on a person’s preparedness to participate in decision-making;

-plain English communications;

-culturally specific communications and culturally sensitivity practices where NDIS user is from a culturally and linguistically diverse background (inclusive Indigenous background);

-demystification of decision-making processes;

-establishing realistic expectations and achievable/agreed goals for decision-making;

-decision making processes and timeframes which are determined in consultation with NDIS participants;

-identifying the key points and spaces for decision-making;

-more consultation with NDIS users to understand their actual decision-making capacities; and

-provision of timely and comprehensive information to ensure informed (and prepared) decision-making is possible.

1. **Who are the best people to help you (or a person with disability) to make decisions? (We call them decision supporters)**

Save Our Sons Duchenne Foundation says this should be determined by the young people/young men with DMD and BMD and their families and carers. This should not be determined from on-high (by NDIA) especially as these are complex conditions which manifest very differently for each individual.

Many young people in our community are achieving extraordinary things such as successfully completing University degrees, travelling overseas. These young people are more than capable of making decisions for themselves and fully participating in decision-making processes (and adding great value to that process). Others, however, are struggling more and may also have co-morbid intellectual or behavioural conditions (autism being a common concern) meaning their capacity for decision making may have more limitations – parents, carers and other significant persons (treating health specialists) may subsequently play a greater role in decision-making.

Decisions as to who are the best people to help our boys/young men with DMD or BMD will also vary over time as the disease progresses and the young person moves through different transition phases in their life. Decision supporters may also vary depending on the issue in question. For example, at a time older boys are making some life choices which may not be consistent with parental preferences and which may represent a conflict of interest for parents.

1. **How can we make sure the right people are helping? For example: that they are building the capacity of the person with disability, that they are considering what the person with disability wants?**

If good trusting relations are developed between NDIA staff (NDIS planners, Local Area Coordinators etc.) and boys/young men with DMD and BMD then it should not be too difficult determining whether the right people are helping as decision supporters. Of course, the constant turnover of staff (a frequent complaint by our community) could be a compromising factor here.

Regular check ins with the boys/young people by NDIA staff would help but this would need to be handled with caution for fear of alienating important decision supporters such as parents/carers who may feel they are being undermined. Feedback could also be sought through surveys, email and other communications.

The levels of complaints could also be a good indicator of whether the right people are helping in the decision-making process.

Training and workshops to build decision-making capacity is also important for both NDIS users and decision supporters and will help address concerns around whether the right people are involved as decision supporters.

1. **What should decision supporters know about so they can help people with disability make decisions?**

Clearly if decision supporters do not have lived experience of DMD or BMD, then they will need to have a good appreciation and understanding of this complex condition and how it may or may not impact or impede decision making abilities of those with the condition.

Those with lived experience of the condition (e.g., family members, carers) will need to appreciate the decision-making capacities of the boys/young men for whom they are decision supporters. They will also need to be cognisant of the principles underpinning the “dignity of risk” and the need for young people in their care, to be able to make decisions in order to grow and develop-however risky that decision may appear. Helping to advise/inform young people of the consequences of certain decisions is critical to this process.

Decision supporters need to be aware of how and what decisions are being made and how they can best facilitate the participation of the NDIS user in this process.

1. **What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.**

Some key measures taken here could include:

-ensuring treating specialists and other health professionals (decision supporters) are available to advise NDIS users and their families throughout the NDIS planning process;

- ensuring the NDIS user is informed of all the options available to them;

-providing clear information and guidance on decision-making and NDIS plans;

-ensuring the NDIS plan making process is flexible, inclusive and respectful of changes in decision-making;

-making sure the NDIS user is fully aware of consequences of NDIS decisions;

-simplifying the process ensuring it is “user friendly” and non confrontational;

-having an openness to ideas and suggestions which are coming from the NDIS user;

-working at the pace and timeframe of the NDIS user – the DMD and BMD community is time poor, so ensuring that the process is not overly burdensome, onerous or bureaucratic.

1. **Are there different things to consider for people with different disabilities or cultural backgrounds?**

It bears repeating but Duchenne and Becker muscular dystrophy are highly complex and progressive diseases which impact people in different ways and at different levels. Subsequently, decision-making processes involving the DMD and BMD community cannot be a “one size fits all” but rather, tailored to individual (and family) circumstances.

For many families, managing the disease can be a 24/7 proposition especially as muscle function declines and the boys lose all mobility. At the time most young people begin to gain increasing independence from their families, DMD/BMD boys become increasingly dependent on theirs (and carers) for the most basic of needs. Many opportunities for independent decision-making are simply robbed from them by way of their physical disability and the limitations which are imposed on many choices/options. It becomes even more important therefore, that those areas of their lives where decisions can be made (including decisions going to NDIS planning) are ones where they are empowered and involved to the maximum extent which is possible. This should not be problematic as the DMD and BMD community is a highly resilient one where parents and carers are forced to advocate for many of those things mainstream society takes for granted. Our community would doubtless embrace more opportunities to be involved in decision making.

A distrust or wariness of authority is an important consideration in relation to some cultural backgrounds -especially where the NDIS user and their family may be from a cultural background where access and participation in decision-making processes is far from the norm and can be quite challenging.

1. **What are your concerns (if any) around people with disability being more involved in making decisions for themselves?**

As should be evident from our responses to date, SOSDF fully supports increased decision making for people with disabilities. This is on the proviso however, that people are fully aware of the consequences of decisions, (and have been made aware of all options) they are properly supported in making decisions, no harm accrues to that person or others because of the decision and the decision is made on a free willed basis – without any inducement or threat.

1. **What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

As raised in one of the consultations we attended, SOSDF believes it to be critical that “traditional” decision-makers and those who are normally making decisions for NDIS users, be prepared to relinquish some control, power and authority – for decision-making to be a truly shared and collaborative exercise. It matters not how much training and support is given to NDIS user and their family/carer, if real decision-making remains the privilege of those who have traditionally made decisions on behalf of people with a disability – be they, bureaucrats, politicians, family members and carers.

As well as developing resources to empower NDIS users, NDIA should also be educating others involved in the decision -making process about the importance of sharing decision-making and empowering people with a disability to be part of those decisions which impact their lives.

**Conclusion:**

Save Our Sons Duchenne Foundation welcomes this consultation paper and the spirit in which it appears to have been written. We firmly believe in the potential of our community to play an active and constructive role in decision-making processes which will consequently, better reflect the needs and aspirations of those living with Duchenne and Becker muscular dystrophy.

Save Our Sons Duchenne Foundation staff and community are ready and more than willing to participate further in consultation on these issues and would welcome any further opportunities for comment.

We are available to be contacted by email on [lance@saveoursons.org.au](mailto:lance@saveoursons.org.au) or by phone

02 9064 9027.

Thanking you for your attention to this submission.

**Lance Dale**

**Advocacy Officer**

**Save Our Sons Duchenne Foundation**

**Support for Decision Making consultation submission**

**Name:** Save our Sons Duchenne Foundation (NSW)

**Date and time submitted:** 8/23/2021 11:46:00 PM

# **How can we help people with disability make decisions for themselves?**

* Resources: No
* Information: No
* Decision Guides: No
* Having a person help: No
* Other: No

# **Who are the best people to help you (or a person with a disability) to make decisions?**

* Family: No
* Friends: No
* Peer Support Networks: No
* Mentors: No
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: No
* Service Providers: No
* Other: No

# **What should they do to help with decision-making?**

No answer recorded

# **How can they get better at helping?**

* Getting to know the participant well: No
* Doing some training on decision support: No
* By having resources and information about providing decision support: No
* Other: No

# **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: No
* They are a registered provider: No
* They enable the participant to take risks: No
* Other: No

# **What should decision supporters know about so they can better help people with disability make decisions?**

* Guidelines for decision supporters: No
* Scenarios or Examples: No
* Information Sessions: No
* Support Networks: No
* Other: No

# **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

No answer recorded

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: No
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: No

# **Are there different things to consider for people with different disabilities or cultural backgrounds?**

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

No response recorded

# **How can we help reduce undue influence?**

No response recorded

# **What are your concerns (if any) around people with disability being more involved in making decisions for themselves?**

No response recorded

# **What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

No response recorded

# **Do you have any feedback on our proposed actions in Appendix C of the paper?**

No response recorded