

20 February 2021



## **Save our Sons Submission: National Disability Insurance Scheme “Planning Policy for Personalised Budgets and Plan Flexibility”.**

The Save Our Sons Duchenne Foundation (SOSDF) thanks the NDIA for an opportunity to make comment in relation to the consultation paper, *“Planning Policy for Personalised Budgets and Plan Flexibility”*. As much of the budget/planning process turns on the outcome of the proposed Independent Assessment process, the comments herein should be read in conjunction with our earlier submission to the NDIA on Access and Eligibility policy and also our submission to the Federal Joint Standing Committee on the NDIS which is currently inquiring into the use of Independent Assessors -and where we will be advocating a series of concerns/issues from the Duchenne and Becker community in relation to the use of IAs.

The following comments were drawn after consultation with the Duchenne and Becker community. While it would be fair to say that this consultation paper did not draw as much interest or contention as the NDIA paper going to Independent Assessors, the NDIS budget planning process is nonetheless critical to our community and there have been a number of key concerns raised.

### **Who We Are?**

The Save our Sons Duchenne Foundation is the peak body representing the Duchenne (DMD) and Becker (BMD) muscular dystrophy community in Australia. 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 critical that the budget planning process is full-proof, responsive, provides the flexibility required by users and their families, is cognisant and informed by future possible contingencies/needs and is developed and implemented in full consultation with families, young boys and young men.**

SOSDF subsequently supports such statements as *“we are introducing greater flexibility in how a participant chooses to use their NDIS funding. Participants will be able to exercise increased choice and control over their plan and use funding in ways that best suit them”* (page 8). This is particularly important with conditions such as Duchenne and Becker muscular dystrophy where progression of the condition (and the subsequent needs and requirements) can be rapid and variable and ever changing over time. Unfortunately, such statements appear to be contradicted by the proposal for Independent Assessments which many in our community believe, will fail to capture the complexities of the disease and will subsequently fail to deliver an NDIS funding outcome, which will provide for the flexibility and choice described above.

SOSDF also questions how *“independent assessments will be used to inform personalised budgets which provide increased flexibility to participants”* (page 10) when generic/standardised assessment tools will be implemented and delivered by an assessor with little grasp of the complexities of DMD and BMD. **How much flexibility can there consequently be in a plan/budget which may be inherently flawed, is not properly informed by health practitioners with expertise and wherewithal with DMD and BMD and which is not properly shaped by the lived experience of someone with this condition?**

SOSDF fully supports the planning policy principles which are set out at 3.1 on page 10. They are a firm and sound basis for moving forward. However, to some degree they become compromised at 3.1 a which states that the new process will:

*Provide personalised budgets which balance individual circumstances and the **sustainability of the NDIS.***

While SOSDF acknowledges that NDIS funding cannot be a “bottomless pit”, we fear that these financial/sustainability considerations could override the implementation of the principles and simply fuel some concerns that these consultation proposals are really about cost reduction rather than providing the support and assistance which is genuinely required.

We also fear that principles going to the participant’s independence in decision-making, participant control and empowerment are potentially compromised by a budget planning process which does not involve the NDIS user until **after** a draft budget has been framed by a NDIS delegate once they have reviewed the Independent Assessment report. Further, that a change to a draft budget appears non-negotiable and will only be made in specific circumstances (page 13). Hardly the stuff of inclusion, participation and empowerment it would seem.

SOSDF supports the provision of draft plans being provided to NDIS users before the planning meeting between the user and the NDIS delegate (page 14).

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

Following are the SOSDF responses to the specific questions posed in the Planning Policy for Personalised Budgets and Plan Flexibility consultation paper.

#### **1. How should a participant’s plan be set out so its easier to understand? How can we make it easy for participants to understand how their funding can be spent?**

Participant’s plans need to be clear, decipherable and easy to follow. Plans need to be agreed and developed in full partnership between the NDIS delegate and the families and young people with Duchenne and Becker.

Plans need to be made more user friendly and less formal. They should be more interactive and visual and available in hard copy and on-line. Suggestions have been made that participants should be able to list their requirements and clearly know where to place them within the plan. Suggestions have also been made that NDIA provide more examples of how funding can be spent and set up more detailed FAQ pages on the NDIS website.

Other suggestions from our community include the use of tables with the different funding categories applicable to that individual as headings with examples of what

might be included underneath. A pop-up box on the NDIS website has also been suggested for when a NDIS user makes a payment request because not everyone remembers what each category is for and may not have the plan in front of them when entering payment requests.

## **2. How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?**

There should be no “curve balls” at planning meetings and no surprises with NDIS users and families being in full receipt of key information prior to the meeting. A list of useful documents to bring to the meeting (e.g., recommended therapy/treatment needs from medical/allied health professionals) should be discussed prior to the meeting along with participant’s own goals/identified needs, health updates, estimates/quotes for capital equipment purchases.

NDIS users and their families should be able to have a support person attend such a meeting and also be able to have a health professional participate – i.e., someone with a relationship with the NDIS user and their family and in this instance, someone with an understanding of the true complexities of DMD and BMD.

Planning meetings should be established in environments and over time frames which are chosen by the NDIS user. Clarification on the purpose and the goals of the meeting plus the planning process should be established prior to the meeting occurring and ideally, everything should be negotiable (inclusive draft budget).

Sally a mother with a boy with Duchenne makes a sound suggestion for how participants can be supported in planning meetings:

*“It is difficult to prepare for meetings when we have so much information. It would be great to have a kind of pre-planning meeting, possibly with a support coordinator or health professional directly supporting the participant so that needs can be discussed, questions asked etc. It is also stressful ensuring that nothing is forgotten, often plans are complex and many of the day to day adjustments are “just what we do” and participants may not know exactly what they can ask for. One meeting can be overwhelming”.*

## **3. Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?**

Supports (be they equipment, therapies etc.) that are deemed essential for everyday functioning by the NDIS user, their families/carers and their (treating) health professionals should always be in the fixed budget- to ensure funds are available for this purpose and not eroded on other assistance/support. However, as highlighted by one parent with a boy with Duchenne, this is a confusing question because equipment like wheelchairs need maintenance and adjustments and this may need to be a more flexible spend.

This same carer is perhaps best placed to unpack issues around the question of what should or should not be in a fixed budget:

*“Sometimes things change quickly and a back support or hand control may quickly need adjusting or changing to suit a progression of the disease or an untimely change (sickness or injury that changes the current situation long term). The idea of flexible budgets sounds promising but not if this means essential items will not be appropriately or fully funded.*

*We have had to fight for quite basic requirements in the past and I wonder if this will be easier or more problematic with a flexible budget. I am also concerned about what might happen if funds are depleted before review. In the past we have had several items not clearly funded by a dollar amount but subject to quote, such as repairs to equipment. At one stage we had three pieces of equipment requiring extensive maintenance/replacement within a one week timeframe- the existing plan meant that we could quickly get these requested and quoted through our regular health professionals and providers, would this still be the case? Better? Worse?*

Caring for someone with Duchenne and or Becker muscular dystrophy is a huge task for the parents/carers of these boys and young men. Not only are there enormous health and social care costs to be borne but enormous sacrifices are made in relation to careers, work lives, social and recreational opportunities. Along with other rare disease organisations, SOSDF subsequently believes that greater support for carers (respite care, additional carer support etc.) should be part and parcel of the essential supports provided in a plan budget.

In 2020, SOSDF commissioned the McKell Institute Report *“Living with Duchenne and Becker in Australia: Supporting Families Waiting for A Cure”* refer

<https://www.saveoursons.org.au/save-our-sons-duchenne-foundation-keynote-report/>.

This report not only highlighted the huge costs met by families dealing with these conditions (refer Appendix A pages 44-45) but also on a number of occasions, the unresponsiveness and delays by the NDIS in meeting some basic needs. Said one mother from Queensland (McKell report page 23)

*“Receiving equipment and support is still just as slow under the NDIS and the amount of paperwork and hoops to jump through is bigger. I’m still waiting for a manual wheelchair after six months even though NDIS only took a few weeks to approve”.*

And says another carer from Western Australia (McKell page 23);

*“NDIS is shocking and causes families unnecessary stress, as they don’t understand the condition”.*

Responsiveness, timeliness and transparency should therefore be the principles at the “heart” of fixed budget determinations. This along with the need for NDIS delegates to be fully cognisant of the complexities of DMD and BMD when determining budgets and the levels of additional flexibility that may be required.

Finally, it goes without question that all of the principles detailed at 3.1 of the consultation paper should be in play here.

**4. How can we assure participants that their plan budgets are at the right level? (e.g. panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements).**

Put simply and given the level of need in the Duchenne and Becker community we believe this will be extremely hard to do -especially if additional funding is not made available to the NDIS and the Independent Assessor process fails to grasp the full complexities of these conditions.

As one mother of a Duchenne boy also pointed out:

*“What if some families are unable to fully express their needs, forget to consider all requirements or are simply having a “good patch” and overlook some less obvious requirements. We already know that more affluent families are receiving better plans than others so guaranteeing equity is important”.*

Another mother of a boy with Duchenne has suggested that consideration must be given to national and international health care standards and recommendations applicable to the participant's condition/needs. Further, this mother argues:

*“If there is any concern/discrepancy between what has been requested and what NDIS plan to fund then hold a case conference between the participant's health professionals (and the participant if they desire) and the NDIA representatives to resolve this matter. Ensure there is an avenue of appeal if the participant believes the NDIA's decision will adversely impact on their health/care/mobility/independence”.*

Regular check ins as proposed at page 21 of the consultation report are supported by SOSDF as one means of helping to ensure plan budgets are at the right level. However, as expressed by participants at a recent Rare Voices workshop (15/2/21) on the NDIS budget planning proposal, “people like check ins but not to be checked up on”. On that basis, check ins should be agreed between all parties, the process and content of the check in discussed before it takes place and any key support persons and/or health professionals welcomed to attend.

As with the process for Independent Assessors, regular feedback should be sought from members of the Duchenne and Becker community and their representatives on whether plan budgets have been set at the appropriate level. Representatives from the rare diseases community should also be included in any existing consultation mechanisms such as the Independent Advisory Council which clearly has a major role in providing voice to NDIS users across a number of sectors. SOSDF notes there are currently four reference groups to support the work and advice of the Independent Advisory Council. We propose that an additional rare diseases reference group be established to ensure the specific (and complex) needs and issues of NDIS users from rare disease communities such as Duchenne and Becker are prioritised in the work of the Advisory Council.

## **5. What do we need to consider for children aged 7 and above in the new planning process?**

To the extent that is possible and practicable, children aged 7 and above need to be involved and empowered in the planning process. The planning process also needs to be flexible and cognisant that needs, and requirements change quickly for DMD and BMD boys and young men.

States one mother of a boy with Duchenne:

*“Needs and requirements change quickly. Families are under a lot of stress, predicting the future is often unpleasant and many families are simply dealing day to day. I think assessors and the planning process need to be respectful of the specific needs of children and youths (and their families) and the process needs to be sensitive to this.*

*As a teacher, I support the proposal for access to early supports. Early supports are essential, and it is unfortunate and detrimental that these supports often “run out” before the child’s needs do, purely because of funding and paperwork”.*

Others in our community are concerned that children are not subjected to additional assessments/reviews unnecessarily. This issue goes back to the concern expressed by a number of parents and carers in the DMD and BMD community, (refer to SOSDF submission on IA’s) that the use of Independent Assessors simply adds another level of stress and bureaucracy onto children, young people and their families – and in an already time -poor, over-stretched community context.

States Julia from South Australia a mother of a boy with Duchenne:

*“The use of reports from a case conference with their treating team should provide adequate evidence of their support needs. The introduction of independent assessors will add an additional cost to the NDIS process (not incurred by the participant but is money that would be better spent in meeting participant care needs) requires a significant amount of additional time for the participant and will also add yet another stranger to their already heavily medicalised life and may contribute to their distress/trauma (depending on the reason for the NDIS need) by having to re-tell their story to another stranger”.*

Great care and sensitivity are therefore fundamental to the NDIS planning process with children.

## **6. What ideas do you have for how people can use their plan more innovatively?**

Plans which are flexible and agreed between the parties should be the starting point. Plans should “push the boundaries” of possibility, and participants should not be discouraged from living their best lives. They should have the full support of NDIS (consistent with the aims and objectives of the NDIS Act) to live independent and full lives (moving out of home, travelling, working). Too often it appears these transition issues and life affirming goals become too difficult and compromises are made.

A suggestion has also been made that on-line support groups be established (for participants and their caregivers) with similar diagnosis/health care needs to enable the sharing of ideas on plan innovation. NDIS could also provide examples on its website on the types of innovation which are feasible and possible. Perhaps one role of the NDIA Advisory Council reference groups could be to suggest innovative plan designs which could be shared with the wider NDIS community?

#### **7. How best to handle the timing of the release of funds into plans and roll-over of un-used funds?**

Our community is of the view that the roll-over of un-used funds is critical given the unpredictable and complex nature of Duchenne and Becker muscular dystrophy. With these conditions it is impossible to know when they may change/degenerate or a critical incident occurs such as an untimely fall, or modifications to a household infrastructure suddenly being required.

What may be “unused” at one point in time may subsequently be essential in ensuring a family or young person can meet a specific need or requirement which was not foreshadowed or present at the time a plan was first developed.

One carer also told us that she believes consideration should be given to rolling over un-used funds where there has been significant delay/impact on the standard level of care (e.g., because of COVID 19 restrictions). These roll over funds would then provide adequate funding to enable participants to engage in more intensive treatment/therapy for longer periods of time when (pre-pandemic) usual care is able to resume.

Our community is also of the view that funds should be released as soon as is practicable particularly in the case of equipment repairs and replacement. Only where there is strong evidence that the participant or their family/carer are not able to manage the finances independently, should funds for the following 12 months not be accessible immediately.

#### **8. How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check in?**

Consistent with views stated above, check -ins should be undertaken in full consultation and agreement with NDIS users and their families. They should not be unilaterally imposed on the NDIS user but something which is viewed as being of mutual benefit and utility (and as part of a partnership). Check ins could occur face to face or over the phone/computer.

Support persons or other health professionals should be invited to assist the NDIS participant in any check in.

Check ins should be designed to discuss how current plans are meeting the participant's care needs and to identify any unexpected gaps and needs. They should be utilised to determine if there is adequate funding remaining in the plan budget to meet the person's needs until the next plan review-with remedial action and top up funding to follow if existing funds are inadequate.

Check ins which are "person centered" (as against check ups) can play a really important role especially in ensuring equivalence in access to the support and assistance of NDIS across the board. In the words of Sally, a Duchenne mum:

*"I think check ins are extremely important. Many families are proactive and seek supports eagerly, but I am concerned that some participants may not be fully accessing their plans and the supports available and I know of families who frequently miss appointments. ....It should be jointly considered whether the check in needs to be face to face or whether a phone call should suffice".*

#### **9. How often should we check in with participants in different circumstances?**

To the extent, which is possible, this should be agreed between the NDIA and the NDIS user/family and regularly reviewed. The NDIS user should have the flexibility to seek a check in on an as needs basis.

The need for check ins could also change over time and as the Duchenne and Becker conditions progresses. Every NDIS user from the DMD and BMD community is different and will have specific needs/requirements at varying times – the frequency of check ins should therefore reflect this individual variance.

#### **10. How can the NDIS ensure positive relationships between participants and planners?**

Ensuring there is continuity in NDIS planners/Local Area Coordinators/Delegates so that relationships, trust and understanding between planners and participants (and their families) have the ability to form would appear to be an important step. Staff turnover issues were strongly highlighted when this question was recently discussed at the Rare Voices webinar on 15/2/21, with a commonly held view being that LAC's are too transient -here today and gone tomorrow.

Clearly, it would seem that some work needs to be done by the NDIA in working through issues of staff retention in a working environment for planners of high stress, emotion and workload.

Honesty, transparency, empathy and responsiveness are certainly all qualities which are sought in planners and which will help to foster positive relations. But more fundamentally, much will turn on the motivations that individual planners bring to the table. Are they motivated to minimise costs to the scheme or are they there to genuinely assist the NDIS user to realize their goals and aspirations - with the assistance of NDIS funding and support? As articulated by one Duchenne mother:

*“Key word: relationships!. By building relationships. By ensuring that the planner’s purpose is to create the best plan for the client, not just to complete a generic one-size-fits all plan. Families and participants need to have their voices heard and their requirements valued. It is great when the same planner can check back in (check ins, new plans etc.) as this builds a sense of continuity”.*

Finally, as with the Independent Assessors, it is also critical that planners be trained or aware of the complexities of Duchenne and Becker muscular dystrophy. Without some working knowledge and insight into these conditions, relationship building will likely flounder as the planner will miss important cues and signals and be ‘out of step’ from the needs/requirements of the NDIS user and family.

#### ***11. How can we best support participants to transition to this new planning model?***

Participants need clear and transparent information- in documents, NDIS websites, NDIA briefings/seminars.

NDIA needs to ensure that participants are aware of exactly what is changing and how this may affect/play out for them. Support people and health professionals should be invited to attend any meetings to ensure the NDIS user and family has someone available to work through the information and its implications with them.

Short YouTube tutorials have been suggested as one possible medium to support the transition process.

NDIA planners need to be available and responsive to any concerns NDIS users and their family may have about the transition process.

**Conclusion:**

The comments in this submission are made in “good faith” and with the purpose of making a constructive contribution to the NDIA proposals on budget planning and process. The comments have been made with our community concerns at the forefront of this discussion.

This submission forms part of a much broader response from SOSDF in relation to the NDIA proposals for change and should therefore be read in conjunction with both our recent submission to NDIA on access and eligibility, but also, our collective response to the Federal Joint Standing Committee on the NDIS Inquiry into the proposed use of Independent Assessors -to be prepared in coming weeks.

SOSDF staff and community are ready and more than willing to participate further in consultation on the budget and planning policy 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 0466899587.

Thanking you for your attention to this submission.

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