



Submissions
The National Disability Insurance Agency (NDIA)

22 February 2021

Re: NDIS Planning Policy for Personalised Budgets and Plan Flexibility

To whom it may concern,



Thank you for the opportunity to respond to the Planning Policy for Personalised Budgets and Plan Flexibility submission. I am responding on behalf of the Genetic, Undiagnosed and Rare Disease (GUARD) Collaborative Australia.

About GUARD

The GUARD Collaborative Australia is a coalition of peak body organisations; Genetic Support Network of Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN) Australia and Genetic and Rare Disease Network (WA). We stand together to represent the voice of people living with genetic, undiagnosed and rare disease and those who support them. We strive for a fair, equitable and collaborative approach to disability, health and wellbeing for all our population members.



Our submission is in the context of the National Strategic Action Plan for Rare Disease, a focussed plan outlining the priorities and areas of action required to improve the lives of people living with rare disease.

We have addressed the consultation questions on the following pages along with our key issues and recommendations.

We would be happy to provide further information about our submission if required.

Kind regards



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Syndromes Without A Name (SWAN) Australia
On behalf of the GUARD Collaborative

About Undiagnosed and Rare Diseases

According to the Australian Government - Department of Health, it is estimated 8% of Australians are living with a rare disease, of which 80% have a genetic origin. It is estimated by geneticists that at least 80% of rare diseases have a disability component that impacts them.

There are over 6000 rare diseases, 75% of them affecting children. Many rare diseases are life-threatening or have a chronic illness associated with them. Unfortunately, 30% of affected children will not see their fifth birthday.¹ Obtaining a diagnosis and/or treatment can be a long and difficult journey. About half of children with learning disabilities and approximately 60% of children with multiple congenital problems do not have a definitive diagnosis to explain the cause of their condition.²

We live in the rapid genomics era where we are discovering new rare diseases every week. Some of these gene changes are complex and we are only just learning about the relationship between some genes and the environment. Discovery can bring hope and possibility, understanding and knowledge, fear and despair. Lack of diagnosis can bring frustration and isolation and limited access to medical, disability, social and mainstream and community supports.

People living with a genetic, undiagnosed or rare disease are amongst the most vulnerable groups in society. Their diseases are highly complex, often chronic, and severely disabling conditions, which generate specific care needs. They are difficult to understand for clinicians and researchers, let alone by the layperson.

For our vulnerable rare disease population, who also present with disability, it is imperative that additional measures such as the NDIS can support them in either maintaining or improving their functional capacity in a fair, equitable and timely manner.

¹ <https://www.mcri.edu.au/content/rare-disease>

² https://www.undiagnosed.org.uk/support_information/what-does-swain-or-being-undiagnosed-mean/

KEY ISSUES AND RECOMMENDATIONS

<p>Consultation and pilot programs</p>	<p>The NDIA should consult with people with disabilities and their families, disability organisations and people who work in the disability industry before making changes to the NDIS.</p> <p>Pilot programs should be developed in consultation with people with disability and the disability sector. They should be reviewed, completed and assessed by people with disability and the sector, prior to going out for further consultation.</p>
<p>Planning Process and Budgets</p>	<p>If independent assessments are to be mandated, we recommend that support budgets not be determined by the results of independent assessments alone. LAC's and Planners should be in a position to adjust budget based on participants needs and individual reports so that participants can secure all the supports they need in their plan to assist them with meeting their plan goals and aspirations.</p>
<p>Planning Meeting</p>	<p>Planning meetings should place participants at the centre and be led by participants or their representatives. Participants or their representative should be supported to lead a discussion on what supports they would like in their plan and what their goals and aspirations are. Reports supplied by professionals also need to be considered and taken into account when developing plan budgets as they are the “experts” in their field and are well placed in understanding participants’ needs.</p> <p>Draft plans cannot be predetermined prior to having a planning conversation with the participant or there representative. The planning meeting needs to be about discussing participants support needs, goals and aspirations and then a draft plan derived by the LAC or Planner for further discussion. The meeting should not be used to work out how the budget can best meet a participant’s needs.</p>
<p>Plan Implementation and Usage</p>	<p>Funds should not be released on a monthly or quarterly basis. Funding should be reimbursed as it is spent without limitations. This will not work well for people with undiagnosed and rare genetic conditions as their life can be unpredictable. They may need intensive therapies at certain times of the year and/or may not be able to access therapies at other times during the year, i.e., for reason of illness or needing to take a break over holidays.</p>
<p>Review process</p>	<p>There needs to be a clear and fair review process if mandatory independent assessments are introduced and they are deemed to be not a true representation of a participant’s functional capacity. Ambiguity around the utilisation of independent assessments needs to be explained particularly around risk and significant behaviours and how supports are allocated when a participant is non-compliant in an assessment.</p> <p>Participants should be able to request a second independent assessment if they or their representative believe the assessment was not an accurate representation of their “usual” functional capacity. This process needs to be ‘certain’ prior to the first assessment.</p> <p>It will be very difficult to gain additional funds in a participants plan to support their needs if independent assessments are solely use to develop plan budgets as independent assessments themselves cannot be appealed and they are linked to plan budgets. We recommend a fairer and transparent review process where participants can appeal their independent assessments or request additional funding to support their needs and assist them with meeting their NDIS goals and aspirations.</p>

CONSULTATION OVERVIEW

Planning Process and Budgets

GUARD is concerned that plans are being derived from the budgets allocated to them based on their independent assessments. Independent assessments alone, (without expert reports integrated and planning conversations) do not provide enough information about someone's functional capacity. This is better understood by having a conversation with the participant and/or their representative as well as taking into account reports written by service providers who know the participant well and are well placed to support their needs, goals and aspirations. Consultation with the participant has to be done as part of the process to develop their plans and budgets.

The pressure for individuals and families derived from a single chance assessment will be extraordinary. This alone will have a negative impact on performance at assessment. Knowing that everything depends on this is a totally unfair burden on a community, where every day can be lived at a different functional capacity – influenced by health, mental health and the environment. Budgets derived from independent assessments should not be used to determine plan budgets alone. Instead, they must form one of the inputs into the planning and budgeting process to ensure there is adequate funding to support a participant's goals. Specialist reports also need to be taken into consideration. It is a false economy to assume that independent assessments will make the process more efficient as the room for error and for plans and budgets to be not sufficient will likely increase the overall time and resources required to achieve a satisfactory outcome.

We still have not seen any evidence from the NDIA that functional capacity assessments are a proven tool for determining support needs and budgets, nor do we have certainty around the intention to have independent assessments translating to plan budgets and how budgets will be arrived at. We need an individualised approach to plans rather than a one size model fits everyone based on what independent assessments bring to the scheme. We are concerned that this model will mean the funding allocated in plans will not be enough for participants to receive supports so they can reach their goals. It will be difficult to increase budgets to include more supports unless new independent assessments are undertaken, which we understand will only be permitted under very limited circumstances. There are many dangers for families in this very linear approach.

Many of the families we represent are vulnerable and rare disease can be regressive, progressive, and episodic. People can perform better on some days than others. A single independent assessment on a given day may not give a true representation of functional capacity and therefore their plan budget will not accurately reflect their support needs. An independent assessment alone cannot possibly understand a complex genetic condition and how the impact on an individual and family.

A draft budget alone has very little meaning. Many participants are unfamiliar with the pricing guide and have little understanding of what supports cost. The pricing guide gets updated about twice per year and we do not know whether updated costings will be reflected in participants plans. Placing the burden on families to fully understand budgets and costs creates additional inequities across the diverse socio-economic and cultural groups who need the support of the NDIA. This will be exacerbated by the pressures of independent assessments.

Draft budgets can only be changed under specific circumstances. There is significant potential for an increase in plan reviews as a direct result of budgets not aligning with participants needs. This will need to be closely monitored by an advisory council and adjusted if the need arises to limit the number of reviews.

We believe that funds should be reimbursed without limitations of interval disbursements. Failure to do so may create hardship and also result in wasted funds on supports participants don't really need at that point in time if they don't understand that some budgets can be rolled over to the next interval.

Inflexible processes like this are this is of concern for our community. A person with a rare genetic condition can be vulnerable and spend many weeks in hospital. Participants may prefer and/or require intensive blocks of therapy and may not have the funding in their plan to do it. Many families choose to give their child a break from capacity building supports over the holidays. This flexibility must be maintained as it is directly related to quality of life and retaining some autonomy for families.

And we know that there are thin markets already when it comes to availability of allied health providers, particularly in rural areas or children being able to access their preferred providers or services for afterschool appointments. Finding providers to ensure funding can be spent in nominated timeframes may also be an issue. A much better approach is to allow participants to claim for supports from the NDIS like they do with the current arrangement.

Planning Meetings

We are concerned that by providing participants with a draft budget (largely derived from independent assessments) and draft plans participants may not feel confident to ask for additional supports or advocate when the draft plan does not meet their needs. Not everyone has the capacity to read and understand them and there is no reference to these draft plans being available in Easy English. We are concerned there will not be adequate discussion around a participant support needs, goals or aspirations for them to receive a plan that really support their needs. Some participants may feel that they cannot challenge a draft plan, literacy, language and confidence will play a role and, this may therefore create inequity of outcomes across socio-demographic and cultural groups.

Planning discussions are important conversations that need to occur prior to participants receiving a draft copy of their plan and budget, otherwise unnecessary risks are introduced and time and resources are wasted. Often a LAC or Planner will not have met a participant before so won't have any prior knowledge of their circumstances and support needs. It is risky to presume the types and level of supports a participant might need without a conversation with them first. If this is done there is a chance that this may cause greater anxiety and stress for participants and their families. Subsequent discussions should take place after the participant has reviewed their draft budget and plan which has been derived from the first planning conversation. Reviewing the draft plan together will then ascertain if the plan will meet the participants needs. The scheme should be participant driven, not by the LAC or Planner. Reports written by service providers also need to be considered prior to finalising plans as these people are "experts" in their field and often have long standing relationships with participants.

Plan budgets derived from independent assessments will mean that Planners have to work backwards designing plans and they will be driven by money rather than what is needed to achieve goals. The planner will first look at the budget and then derive a participant's support needs so they can be accommodated by the budget. This may mean that a participant may not receive the supports they need to maintain or increase their child's functional capacity as the plan budget does not align with their needs.

Plan lengths should be driven by participants requests and discussed with participants at their meeting (within reason). It should not be up to the delegate to select the length of the plan. Participants may, prefer different plan lengths particularly if their condition is episodic, fluctuates and may lead to deterioration of their functional capacity.

Plan Implementation and Usage

We know that it is harder for people who choose to self manage their plan to receive support coordination in their plan, particularly for more than one plan. Independent assessments may lead to an even greater need for support from a support coordinator and LAC's may increasingly need to support people to use their new plan flexibilities and in different ways, particularly if supports are not sufficient.

It is already difficult to find some supports and services due to decreasing numbers of allied health professionals, particularly in rural and remote areas. The long waiting lists for well regarded allied health professionals and service providers have been clearly documented and this adds to the problem of participants spending the support budgets in their plan. Any increased ambiguities and uncertainties will exacerbate this problem for families. People who are already experiencing isolation, disadvantage and financial hardship may find it harder to use their plan without additional support.

Support coordinators who have a good understanding of the genetic and rare disease community can be very difficult to find. We know of many participants who could benefit from support coordination in their plan but have not received it. They then struggle to understand their plan and find supports.

One way to solve this problem would be if LAC's were allocated more time to assist participants with implementing their plan and finding supports and services. High staff turnover within the sector appears to be a problem and often participants are unaware that their LAC has moved on as their newly allocated LAC has made no contact with them until it is time to set up a plan review meeting for the next plan. This lack of continuity is also a source of stress as families are again required to tell their story to a stranger.

It is likely that some plans will not have enough structure or detail in them for some participants to use. Some participants have relayed to us that they want to see more examples written in their plan because they were not clear on what support their plan would fund. Many participants were not even aware of the NDIS pricing guide. Many that were aware conveyed that it was difficult to read and it was poorly laid out. The terminology used in the pricing guide is regularly different to that in plans and the portal creating further confusion.

Review Process

The lack of options available when a budget and plan are deemed inadequate by families is unacceptable. There must be a system allowing families to request a review of an independent assessment if findings are disagreed with. These assessments may impact eligibility to remain in the scheme and are linked to plan budgets. The budget derived from an independent assessment may not be enough to cover a participants support needs and goals. Furthermore, the NDIA is yet to provide evidence that supports functional capacity assessments are the best proven tools for determining support needs and budgets, or even how these assessments would be translated into budgets.

It is important that the NDIS consider "expert" reports from service providers that support participants, particularly when planning budgets and allocating supports in plans. They are better positioned to understand the supports participants needs in either maintaining or improving their functional capacity. There is still so much unknown about rare genetic conditions that an assessment like the ones proposed by the NDIS will not capture a true understanding of our communities needs. Some rare diseases are regressive, progressive, and episodic, so if a rare disease participant was assessed on a "good" day, they might receive a very different score on their assessment than on a day where the condition impacted their disability more.

We would like the NDIA to provide more details about how to seek second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances. We do not know what constitutes a “significant change” in a person’s capacity or circumstances and this concerns us as it may be subjective and it should be transparent. Unless another independent assessment shows a decrease in functional capacity, it will be difficult for a participant to gain additional funds in their plan to support their needs.

Even with an AAT review, the AAT is unable to review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. We are concerned that without the funding in their plan to purchase the supports participants may not be able to meet their goals and aspirations.

Only delegates can make a decision that an applicant does not need to complete an independent assessment where there is a risk to safety or an assessment is deemed inaccessible or invalid. This concerns us as what constitutes risk and safety can be subjective. Surely a participant or their representative is much better placed to evaluate what constitutes risk and safety for a participant as they have a better understanding of aggressive and dangerous behaviour, emotional triggers and trauma compared to someone they have never met. We also note that emotional trauma can arise well after an event.

We would like the NDIA to disclose what the grievance process for applicants who are dissatisfied with an independent assessment, their assessor, or the assessor organisation. Participants cannot review a decision made by a delegate, to not grant an independent assessment, if they disagree with the decision. Participants should be able to appeal this decision.

Participants should be able to request another independent assessment under less rigid appeal criteria. They should also be able to request a review of the budget figure attached to their independent assessments if there is not enough funding to receive supports for them to be able to achieve the goals.