



Submissions
The National Disability Insurance Agency (NDIA)

22 February 2021

Re: Access and Eligibility Policy for Independent Assessments

To whom it may concern,



Thank you for the opportunity to respond to the Access and Eligibility Policy for Independent Assessments 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

Heather Renton
Chief Executive Officer
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-swan-or-being-undiagnosed-mean/

KEY ISSUES AND RECOMMENDATIONS

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| <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>Presumptions</p> | <p>The NDIA has approached independent assessments as if the new legislation has been adopted. We consider this to be misleading and may be causing concern to participants unnecessarily. We recommend the NDIA stop presuming that the legislation changes around independent assessments and other changes to the NDIA Act 2013 will be passed by the government.</p> |
| <p>Better Use of Funding</p> | <p>Funds could be better spent on improving the NDIS rather than introduce mandatory independent assessments. These would include providing participants with the supports they need to achieve their NDIS goals and training staff so they have a better understanding of disability (including undiagnosed and rare genetic conditions).</p> |
| <p>Review Process</p> | <p>If mandatory independent assessments are introduced, there needs to be a review process so participants can appeal their results from an independent assessment if they believe them not a true representation of their functional capacity. There is too much ambiguity that needs to be explained around risk, and significant behaviours, and how they allocate supports when a participant is non-compliant in an assessment.</p> <p>We disagree with this decision that participants can only request a second assessment where the assessment was not consistent with the independent assessment framework, or if there has been a significant change to their functional capacity or circumstances. Participants can perform better on some days than others, particularly when they are impacted by a genetic condition.</p> <p>Unless another independent assessment shows a change in functional capacity, it will be very difficult to gain additional funds in a participant’s plan to support their needs and goals. The AAT cannot review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. SWAN considers this a big flaw in the review process because it is favours the NDIA over the participant.</p> <p>Independent assessments results should be easier to appeal against. Participants need to be able to either request another independent assessment under less ridged appeal criteria or be able to request a review of the budget figure attached to their independent assessments, if it preventing them from getting the supports in their plan they need to be able to achieve their NDIS goals.</p> |

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| Reports | <p>Reports and letters provided to the NDIS that are written by clinicians, allied health professionals and service providers need to be considered when allocating support and funding in plans. These reports are written by “experts” in their field. These service providers have a much better understanding of participants’ support needs and goals than those who have never worked with them. This is particularly important when supporting participants who have an undiagnosed or rare genetic condition, as often there is very little information about the condition.</p> |
| Support Budgets | <p>Support budgets should not be allocated solely on the results of independent assessments. Instead, conversations need to be had with participants or their representatives to find out from them how they wish to be supported and professional reports need to be considered.</p> |
| Transparency | <p>The NDIA needs to be more transparent about independent assessment. We are concerned with governance issues such as how NDIS assessments can be considered independent when the NDIA is the one in charge of the tender process.</p> <p>The NDIA needs to state an allocated maximum number of times approved for an independent assessment to be completed.</p> <p>The NDIA needs to list what the criteria and professional qualifications are for administrating independent assessments. The current statement that it is not limited to the listed professionals mean it is ambiguous and unclear.</p> |
| Thin Markets | <p>The NDIA should state how they intend to address the shortage of allied health professionals, particularly in rural areas, due to allied health professionals leaving their profession to become independent assessors. They should also be transparent about what impact this shortage will have on families and service provision.</p> |

CONSULTATION QUESTIONS

Overview of Independent Assessments

The GUARD Collaborative Australia opposes the introduction of independent assessments in most scenarios and hope that through this consultation, the NDIA will realise that the introduction of mandatory independent assessments is not the way to improve the NDIS. We believe the money would be better spent on allocating sufficient funding in participants plans that supports them to meet their NDIS or goals and on staff training so they understand the needs of people with disability.

We are disappointed that the second pilot program around independent functional assessments for the NDIS is yet to be completed prior to a consultation such as this one.

We feel that the government has misinterpreted what the Tune review outcomes. There was no recommendation of functional assessments to be administrated prior to a planning meeting. Legislation around independent assessments has not yet been passed in parliament and the NDIS presumes that independent assessments will become mandatory in most cases. This has been confusing and misleading for participants.

We are concerned about the lack of a review process for families if there is disagreement with the independent assessment. We are not comfortable that independent assessment results will inform participants plan budget. Planning meetings are meant to be driven by participants so they can gain access to services and supports to help them meet their NDIS goals.

Budgets from independent assessments should not be used to determine plan budgets alone. Instead, LAC's and Planners should be in a position to adjust budgets 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. It is unclear if this will be the case.

Our members have told us that "expert" reports written by service providers who often have built long standing relationships with their clients over time are not always read. These reports need to be understood and considered when creating plan budgets. It is unfair to create plan budgets solely around the result of independent assessment, reports have to be considered. The NDIS is meant to create individualised plans with plans designed around participants support needs. We fear this may be less apparent as support budgets are linked to individual assessment reports.

Planning meetings are meant to be two way conversations about what supports participants would like in their plan, and their goals and aspirations. From these conversations, plans should be written with budgets for support items attached. The new approach the NDIA is recommending is that the LAC or Planners show participants a draft budget that has been derived mainly from their independent assessment and can only be changed under specific circumstances with very little avenue to review.

Showing a participant a draft budget prior to their final plan has little value as many participants are not familiar with the pricing guide and the cost of NDIS funded supports. The pricing guide gets updated around twice per year and often, participants are unaware this has happened. There has been no reference by the NDIA as to whether the new plans will reflect this in a participants budget. The other issue with showing participants a draft budget before a draft plan is that it can only be changed under specific circumstances. Participants cannot ask for a review of a draft budget.

The NDIS is proposing participants have a planning meeting after their draft plan has been developed by the LAC or Planner and shown to a participant. Not every participant will have the capacity to read it, let alone understand a draft plan. These drafts should be available in Easy English when the plan is in draft format and then again when the plan is finalised for a person who requires

it. The NDIA has made no reference to whether they will provide a participant who requires it with an Easy English version of their plan.

The planning meeting may involve trying to fit supports into budgets if the supports in a participant's plan are not what the participant wants. This is concerning for our community who often have unpredictable needs. It may mean a participant may not receive the supports they need to maintain or increase their functional capacity or budget in their plan to purchase the supports they need. The NDIS is meant to be tailored to the individual participant's needs and conversations about what participants want in their plan need to happen prior to them receiving a draft plan.

We are concerned plans will become more difficult to review as plan budgets are linked to independent assessments. It is very difficult to lodge a review of an independent assessment. A second assessment will only be granted where the assessment was not consistent with the independent assessment framework, or if there has been a significant change to a person's functional capacity or circumstances. Unless another independent assessment shows a change in functional capacity, it will be very difficult to gain additional funds in a participant plan to support their needs and help participants meet their NDIS goals. Even participant an appeal at the AAT, they cannot review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. GUARD believes independent assessments should be easier to appeal.

Learning and Access to the NDIS

Our community has made clear to us that people have difficulties learning about the NDIS and are still unsure how to access the scheme. In some ways, the scheme favours people with high health literacy, more economic strength and better networks and disadvantaged people who cannot afford to pay for reports up front to attach to the access request form, families who struggle to understand the forms and process and families who already feel isolated and excluded.

GUARD sees removing the access lists in the operational guidelines as a positive step as it will hopefully remove some of the inequities within the NDIS. For example, there were very few rare diseases listed on the lists. It is clear from our community that it was easier to access the scheme if you had one of the genetic disorders defined on the list. This has still prevented questions such as "So when will you grow out of this condition?" and "When will you be cured?"

We are also aware that many of our families have been denied access to the NDIS despite meeting the access criteria. It is clear that one of the contributing factors to this has been that the assessors have little knowledge about genetic conditions and struggle to understand medical reports. Even clinicians do not understand a lot about many of the rare diseases our families live with. This is because, as the name suggests, they are "rare" and many of them have been newly discovered in the last decade.

We hear from families of their concerns about whether the NDIS has actually read their submitted reports. As far as we can tell, there is no guarantee when you submit them that they will be read and understood. This has sometimes been reflected in inadequate plans being given to the participant, for which they have then had to lodge a review of a reviewable decision.

Sometimes it is difficult for clinicians to state whether the manifestation of a rare genetic condition is going to be permanent. New technology, gene therapies, clinical trials and research are developing all the time. Just look at what happens when every effort is put into curing a disease such as COVID-19. We do however, understand that even if effective treatments can be found and treatment is accessible for all (rare disease treatments are usually extremely expensive) that the impacts already experienced by individuals are most commonly irreversible and the disability lifelong.

The medical terminology that the NDIS needs to understand should be taken from reputable sources such as the World Health Organisation or government definitions. It is important to note the difference between palliative care in adults and palliative care in children which has a more holistic approach.

Undertaking an independent assessment

Our community clearly believes and is worried that the proposed independent assessments will have a negative impact on their participants and their families. Some participants are fearful of strangers and tests. For families who so often live with the “unknown”, independent assessments will add to their uncertainty. Our families so often don’t tick a box with how their disease will develop. They often don’t know whether it will be regressive, progressive or episodic. The same approach to planning instead of a more individualised approach, will not work well for our families and goes against the principals of the NDIS Act 2013.

Parents are concerned about their child being assessed as non compliant through testing. They are concerned this will affect their child’s plan budget. Assessment results cannot equate to set budgets in plans alone. This was never the way the NDIS was intended to work. We believe the proposed money the NDIS plans to spend on independent assessments could be better spent and more effectively allocated to improve the quality of life and future prospect of people living with an undiagnosed, genetic or rare condition. Many people are confused about independent assessments and are extremely anxious about their introduction which is understandable. These concerns are already impacting families.

Not enough information about independent assessments has been disclosed. Families need to know how many attempts a participant can have at finishing an independent assessment before the results are deemed invalid because the test could not be completed? What will happen where participants who have a medical condition as well as disability and are unable to concentrate for an extended period of time before they fatigue? And we are concerned that these tests were designed for a different purpose, not specifically for the NDIS.

Participants with multiple and complex disabilities may struggle to select an assessor who might be best placed to administer the assessment. . In most cases a multidisciplinary assessment would be required to provide a full understanding of a child’s daily function.

Participants who have a limited grasp of the English language or an intellectual disability, particularly when this is the case for parents completing a Vineland assessment for their child cannot be left behind. Will there be an Easy English version of this test, will there be visual prompts used? We are aware through anecdotes from our community that interpreters don’t always translate things correctly and there are issues with English words not existing in all languages and the other way around. Not understanding or misinterpreting the terminology could lead to inaccurate assessments taking place.

Genetic and rare disease can be unpredictable. Situations can change rapidly, from a person being calm to have an aggressive outburst or seizure, bringing an assessment to an abrupt end. This may be confronting for all involved. Sometimes these situations are exasperated by stress. How will this impact the assessment, the assessee and the assessor? Families do not want to feel bad when their child cannot complete a task.

The notion of the NDIA selecting assessors is problematic and a potential conflict of interest. This could lead to a questioning of the independence of the process. It concerns that the proposed assessors are from a range of health professionals but the NDIA states they are not limited to the list specified by them. The NDIA does not specify who else could become an assessor. Will this include LAC’s and Planners or people without lived experience of disability or industry experience of working

with people with disability? Will this be clarified in the independent assessment framework. The lack of understanding of disability among LAC's and Planners already causes problems with participants gaining adequate funding in their plans to meet their goals.

We are already concerned about diminishing numbers of allied health professionals in regional and remote areas and any acceleration if allied health professionals are used as independent assessors. There simply won't be enough allied health professionals to service participants, particularly in regional areas.

A number of undiagnosed and rare genetic conditions include autism or autistic presentations as part of their condition. This means that high levels of anxiety impact their functional capacity. Will these participants be offered a choice in between what test they want - the PEDICAT (Speedy) or PEDICAT ASD (Speedy)?

GUARD is concerned that the introduction of independent assessments will be used as a way for participants to exit the scheme prematurely, which shifts away from where you are a participant for life if you have a permanent disability.

Exemptions

The exemption process for independent assessments is unclear. Who decides if safety concerns are involved? Surely a participant's family is much more aware of their emotional vulnerability and safety and has experience impacting their mental health wellbeing than a complete stranger? Stress brought on by experience, which can trigger feelings of judgement or guilt for individuals, such as assessments, can bring out the worst in our families. Being exempt from an assessment should not impact the amount of funding in plans usually allocated with assessment ratings.

Review process

One of the main reasons we are so opposed to independent assessments is that there is no means to request a review of the assessment if you disagree with the findings. Depending on how the questions are answered, it could impact on your eligibility to the scheme or determine your plan budget. The assigned budget may not be enough to support a participant's needs. Furthermore, the NDIA is yet to share evidence that supports functional capacity assessments as proven tools for determining support needs and budgets, or how these assessments would be translated into budgets.

There is still so much unknown about rare genetic conditions that an assessment such as those proposed by the NDIS will not capture participants needs. Some rare diseases are regressive, progressive and some are episodic, so if a 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. This is why it so important that 'expert' reports from service providers that support participants are considered when determining plan budgets.

More clarity is required around seeking a 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 don't know what will constitute a "significant change" in a person's capacity or circumstances and could be subjective.

We are baffled as to why it is only the delegates decision as to who does not need to complete an independent assessment where there is a risk to safety or an assessment is deemed inaccessible or invalid. Surely a family member would understand the risk and safety to the participant they represent, much more than a stranger. Emotional trauma can surface after a negative experience,

not just during it. We think this decision should be made in partnership with the participant or their family as it is too subjective just to be made by the delegate.

There needs to be more clarity around the grievance process for applicants who are dissatisfied with an independent assessment, their assessor, or the assessor organisation. We are hoping this is explained more in the quality assurance framework. We are worried that the delegate's decision not to grant an exception for an independent assessment is unable to be reviewed.

The delays that this process will inevitably deliver in the provision of services is also alarming. People living with an undiagnosed, genetic and rare condition can degenerate quickly. Months and years cannot be lost through bureaucracy while a person's and family's quality of life diminishes. The lack of clarity around this process and its implied implementation is causing despair in our community, where hope is such a precious commodity. This must be addressed.

It will become harder to appeal a planning decision because support budgets are linked to independent assessment which cannot be appealed at the AAT. If participants do not have the funding in their plan to purchase the supports they need to meet their goals and aspirations, we are concerned it will be very difficult to gain further funding without another independent assessment which are only allowed under special circumstances.

Independent assessments results should be easier to appeal against. Participants need to be able to either request another independent assessment under less ridged appeal criteria or be able to request a review of the budget figure attached to their independent assessments if it is preventing them from getting the supports in their plan they need to be able to achieve the goals in their plan and aspirations.

Communications and accessibility of information

There needs to be more clarity around how assessments will be conducted if participants or their representatives have little grasp of English or require the assessments to be provided in Easy English or with visual supports. More consultation needs to occur with these communities, including participants from culturally diverse backgrounds, to determine how best to support them.

Participants should be able to choose between receiving their independent assessment either as a summary report or a full report.

The NDIS has to be transparent about how they propose to allocate support budgets and how much will be equated to each different assessment and their scores.