



**Submission to the National Disability Insurance
Agency (NDIA) in response to Consultation
Paper: Access and Eligibility Policy with
Independent Assessments (IA)**

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocate
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

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About Family Advocacy

Family Advocacy provides advice and support to families so they can advocate with or on behalf of their family member with developmental disability (hereinafter disability). Our goal is to advance and protect the rights of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. Our work includes representing the rights and interests of a person with disability to Government regarding legislation, policy, funding, monitoring and practice in areas that impact detrimentally on people with disability.

Family Advocacy was founded and is governed by families of people with disability and is funded by the New South Wales (NSW) and Federal governments. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they can support their family member to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles. This includes making the most of emerging opportunities for self-directing supports and to use creative and innovative models of support through individualised funding.

In this way, we believe our purview lies in alignment with the overall objectives of the National Disability Insurance Scheme (NDIS), with a similar aim to provide transformational benefits to the lives of people with a disability. Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this.

Our submission

Family Advocacy appreciates the opportunity to provide input to the NDIA on its Consultation Paper: Access and Eligibility Policy with Independent Assessments.

This submission is based on a survey of 141 people with disability and/or their family members and shaped by the accumulated knowledge of families' experience that spans nearly 30 years in advocating for supports, enhanced policies and practices that value the

lives of people with disability. For confidentiality reasons, the names of anyone quoted from the survey have been deidentified.

We note three other NDIA papers are also open for public comment.

In relation to the [Consultation Paper: Access and Eligibility Policy with Independent Assessments](#), we support the views of People with Disability Australia (PWDA).

For our views on the [Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility](#), please see [Disability Advocacy Network Australia's](#) (DANA's) submission which we have endorsed.

For our views on [Supporting Young Children and Their Families Early, to Reach Their Full Potential](#), please see [Children and Young People with Disability Australia's](#) (CYDA's) submission which we support.

Our main concerns

The NDIS is underpinned by the broader vision of a fully inclusive society where a person with disability has more choice and control in their life. We strongly support this notion. We are in agreement with the general intention behind independent assessments which is to provide more equity and consistency to enable fairer decision making processes. We support the cost barrier being removed so people with a disability can access the scheme more equitably. We support the principles of this policy which includes that the process will:

- a) be accessible, holistic and strength-based, recognising each individual's life circumstances and environmental factors
- b) involve the individual in decision making processes that affect them to the fullest extent possible, and supports them to make decisions for themselves
- c) be based on nationally consistent tools and allows for approaches to be tailored to individual needs
- d) acknowledge and respect the role of families, carers and other significant persons in the individual's life where applicable
- e) be inclusive and have safeguards that ensure the individual's respect and dignity are upheld.

Unfortunately, from the experiences shared by our families, there appears to be a significant disconnect between policy and practice within the NDIA. We are very concerned with the

proposed individual assessments for accessing the NDIS or renewing a plan in its current form. Results from our survey with supporting families has shown that 81% were against the plan to introduce the NDIS Independent Assessment (55% very negative, 26% Slightly negative). Many people are worried, defeated and overwhelmed at the idea of independent assessments. They believe it tips the balance of choice and control away from people with disability over to the bureaucracy.

Like our family members who support a person with a disability in their lives, we are extremely concerned about the idea of using independent assessments on new people and existing NDIS participants. We are concerned about how it will change the NDIS that we fought for, it won't be the NDIS we have now, and it won't be the NDIS that could emerge with positive improvements.

Many disability advocacy organisations and representative organisations share our concerns, and have become united in their view that the NDIA's planned changes to the NDIS, including independent assessments, will be harmful to people with disability.

We are also concerned this proposal of independent assessments could breach the human rights of a person with disability under the United Nations Convention on the Rights of Persons with Disability (CRPD), and the National Disability Strategy (NDS), the key legal instruments under which the NDIS is underpinned. The proposed scheme provides less coverage to individual people with disability which could bring them to more disadvantage.

We urge the NDIA to consider the human rights of people with disability and the original objectives and principles of the NDIS Act and NOT implement the proposal for independent assessments.

We share the concerns from our families who represent a person with developmental disability as follows:

Independent Assessment (IA) process rushed through without proper consultation with people with lived experience

"Introduction of this new process appears rushed. It comes across as if the NDIA has a hidden agenda. It ignores the working relationship Participants have had with health providers over many years and who know them very well."

"Upfront consultation will mitigate many misconceptions/ misunderstandings/ anger/ frustration on all fronts."

Like the initial NDIS rollout period, many of our survey respondents feel this new independent assessment process is being rushed through, without proper consultation, without co-design of people with lived experience, and without having had a proper pilot study that is statistically significant.

We note in the first pilot, only 145 people filled out the survey, which represents a very small percentage of the total number of people in the NDIS (approximately 400,000), so a far cry from representative. We also note for the second pilot, of which 4,896 people were invited to take part, only 215 have accepted, with many yet to respond, again hardly representative enough to make such a significant change to the NDIS process and its implications for every participant.

The majority of survey respondents believe the government should design a proper consultation and co-design process with people with disability and their families to fix the problems of the NDIS. There must be genuine and deep engagement and not tokenistic consultation with people with disability. In our experience, we often find that the term "consultation" is applied by government departments as a knee jerk way and we are concerned that simply listening to the views of people with lived experience of disability is a shallow way to engage them. We have certainly experienced the situation where an agenda is predetermined by a government department and then information/input is sought with very rushed timeframes/deadlines and that is as far as it goes. It feels the same in relation to the introduction of the IA.

In accordance with the CRPD, we advocate for a deeper engagement process where people with disability have shared responsibility, are active partners in co-design, making decisions and shaping policy/systems. This also includes the review, monitoring and reporting processes.

Adding another layer of bureaucracy will add to the stress and confusion for people with disability and their supporting families

"NDIS was pretty chaotic at the very start for some. Things have more or less "settled down" in the last year or two. Now NDIS is looking to venture into Independent Assessment which will kick-start another round of chaos and mental stress for most

NDIS participants especially we are still in the midst of COVID uncertainty. I strongly believed that the current therapist is a better person with greater knowledge of the participant capability over the months of treatment. It is definitely harder for an external professional to gain an accurate insight within a 20 minutes timeframe.”

If the NDIA progress with their intention to incorporate an independent assessment process then this will evidently add another layer of complexity, add to the confusion of people with disability and their families, add to their mental and emotional stress and create mistrust in the NDIA as it arouses fear that this is a cost cutting exercise.

Remove the cost barrier so people with a disability can access the scheme more equitably – there are other options

In the consultation paper, this is one of the main rationales for rolling out IAs. But it will still involve having to pay for specialists’ reports related to getting a diagnosis and proving their disability is likely to be permanent. To assert that IAs are the only solution to the cost barrier in their current form is misleading.

There are many other policy options that could be explored to assist with the cost barrier, for example, the NDIA could fund assessments with a practitioner of the participant’s choice – as choice and control is one of the main objects of the NDIS.

The need to be able to review the independent assessment

In our survey, 97% thought there should be opportunities to review or challenge the outcomes of independent assessments.

“There should always be an opportunity to review decisions. It’s called due process. Especially when the assessors are employed by the NDIA, they are far from independent.”

“It’s impossible to get all assessments 100% correct. There is always the possibility that the first assessor may have made an error or missed important information regarding the person with disability.”

“It would be very dangerous and stressful if this process were not open to appeal.”

Of tremendous concern to people with disability and their families is to inability to challenge any assessment undertaken to obtain access to the Scheme or to challenge plan decisions. It is simply unacceptable that an appeals process is not built into any process that has a direct impact on a person with disability.

To not provide this option to appeal the IA, would be a denial of due process and fairness to the participant. It will also feed into the fears and skepticism that people with disability believe this IA process is a cost cutting exercise at the expense to the participant. We have heard of many examples in the past where planners have made errors including errors of judgement – human errors are inevitable and this always needs to be acknowledged in the design of the processes. When we are talking about people’s lives and in particular the lives of the most vulnerable in our society; it is absolutely essential that the IA can be appealed.

Furthermore, it should be critical to any design of assessments that going through the full appeals process should be a last resort and there should be multiple ways to address errors or misunderstandings built into any process capturing this information. Any intention for the NDIA not to built a system that reflects this would show a complete lack of insight into the feedback of people with disability and families.

Loss of choice and control - the need to know the person with disability and their functionality of their everyday life

“We have professionals we can work with who know us and they can do any required assessment. Having someone come in and do an assessment on our child who we don't know and have not hired is damaging to our child and us. It takes away our choice.”

“I don't understand why they are taking this move back towards bureaucracy choice and control rather than our choice and control.”

“People with disabilities have complex needs and an assessment done by someone other than the people who have spent the time getting to understand these needs will not be adequate.”

“I think independent assessments should only be offered to those who do not provide their own assessments. Allied health professionals do use standardized assessment

tools and there are many advantages to them providing their additional knowledge of their clients, as each person's disability is unique and a true picture needs more than simply standardized test results. People with disabilities generally have had a multitude of assessments and for most of them their disability does not change at all or very much over time. Having an assessment is stressful for people with a disability and those who love them and they should be able to choose who they feel comfortable with (ie a known, well recommended or respected chosen professional) rather than be allocated a stranger to give such personal information to.”

Families have expressed that the intended process is highly flawed and presumes all people with disability can share their whole life with a complete stranger, and that this stranger can get a full picture of their functional capacity within a 3 hour time frame. The proposed process completely negates individual choices as well as the need for a more nuanced approach to adequately assess individuals. The assumption from the NDIA that such a proposed process is considered adequate calls in to question the lived experience of disability of NDIA decision makers.

The need for a quality independent assessor

“NDIS was already not going a good job with LAC/Planner system as the turnover is high and key communication often get miscommunicated or distorted and impact funding negatively. With IA, this process will be worse.”

“Based on my history with some NDIA planners and LAC I would question the qualifications of the assessor and the lack of background knowledge of the participants. I feel that independent assessment would be detrimental to the majority of worthy participants and that this would be another “cost cutting” project that is destined to fail. As we say in our household “another pink batts scheme” where every “woman, man and their dog” suddenly become “qualified independent assessors” with no life skills or background or adequate training and qualifications.”

“The best person to make an assessment is someone who knows the client and their personal, family, health and social history - otherwise a formulaic assessment is made with little or no bearing on reality.”

“What sort of life experience do they have? How will participants be treated?”

“All assessors of NDIS should have a thorough and reliable knowledge base and experience in the area of disability that they are assessing - eg. Assessors of participants with an intellectual disability, should have a thorough understanding and experience of intellectual disability and the subsequent needs of participants they are assessing.”

“I believe that the complexity of need requires people to spend time to get to know the participant and I think that it would be an enormous waste of public funds to have assessors spend the length of time that would be required when the PWD's specialists and carers already have the independence, qualifications, training, expertise and time spent with the participant. Rather than assessors, we could use some quality specialists to make sure that everyone is getting a fair deal so that the plans being developed reflect the true needs of the participants and not just the capacity of their families to advocate for them.”

“Qualifications alone are just academic consideration. Emotional and sensitive understanding of participants and their needs are more crucial. You can't understand a person who has challenges in communication and understanding and has intellectual disability, mental health issues in one interview. Some participants are so overwhelmed with new faces, harsh tone, facial expression with no smiles, cold room, closed doors etc to even be able to concentrate in any interaction even if minimal.”

It is imperative that should it go ahead, the IA process must have well qualified, experienced and knowledgeable assessors. Our families' experiences tell us that many LACs do not have enough training, experience or a compassionate attitude. How do we ensure it will not be the case with independent assessors? This will take intentional effort from the NDIA in relation to rethinking its processes and ensuring that contemporary values based training is provided to its employees. Family Advocacy would welcome discussing these values based training with the NDIA.

Standardisation comes at the cost of being person-centred

“Sounds very simplistic and one size fits all without much context about the individual.”

“One feedback from a volunteer participant/mother in the pilot was that questions were not well thought out, answers were misapplied, the assessor did not understand participant's answers and participant's real capacity and mother/support person not allowed in interview so no one present to clarify or explain. The young man (participant) was asked if he knew about financial planning and he said ‘yes’. But he did not even understand the value of money. He thought the fact that he can use the ATM and buy some small items on his own was what it meant. Assessors are not sensitive to the person's needs and capacity. This approach will cause a lot of grief.”

“I understand that this is a universal, one-size-fits-all approach. I understand that the NDIS wishes to standardise, streamline and automate the application process, with the rates of applications and reviews increasing. There is a risk that Standardisation will fly in the face of the NDIS being person-centred, as its intake procedure becomes more like Centrelink's assessments. It makes it difficult for people like ourselves, who fall between the cracks with their high needs that are neither covered by medical care nor by disability support. On the other hand, it could mean a more thorough assessment for cases of clear need. This will really depend on what factors the NDIS will include as requiring disability support, and on how thorough each pre-defined questionnaire is. I have heard that people who underwent it found it quite uncomfortable. It needs to take into account the family in which the person is living, as his / her condition is a condition of the entire family. The whole family is impacted, and the NDIS needs to include this factor in the provision of supports.”

“I have read plenty of feedback from people who had (trial) Independent assessments. I am very concerned that these assessments are generic, not case-specifically adapted box-ticking exercises, conducted by people with no or limited lived experience and limited understanding. The purpose of the whole exercise clearly seems to be to save costs, rather than to improve quality of assessments. I am concerned on missing out on vital, necessary and reasonable NDIS support, due to incompetent, non-understanding assessors. Training alone does not make an assessor competent!”

The need for NDIA to acknowledge that “Family is the natural authority of the person with disability”

“Input from people associated with the person at a frequent level, both family and ancillary, should be taken into account.”

“...no one else knows better about the participant than the family.”

The families’ experiences we have shared highlight the importance of the NDIA recognising that the family is the natural authority for their family member with developmental disability. Families ought to be recognised as having credibility and experience in understanding the impact of their family member’s disability has on their everyday life, as well as the most optimal support arrangements for their family member with disability. Indeed, the acknowledgement and respect of the role of family in the lives of people with disability is one of the general principles listed to guide the actions of the NDIA.

In regards to a person with developmental disability, it is most important to have a family member involved and present in any meeting with the IA.

Exemptions

88% of families who have a person with disability in their life agreed there should be certain circumstances when a person may not be required to complete an independent assessment. The most common examples were:

- Everyone should be exempt!
- *“People with disabilities circumstances are so individual that trying to classify and box them just does not work”.*
- *“An unknown person with little experience of my child should not determine their eligibility”.*
- when the person with disability does not have a support person/family member who knows them well and who understands their life, routines, interests, strengths and makes informed decisions about their supports. This is absolutely essential for invisible disabilities such as intellectual disability, autism and high anxiety where the person with disability does not understand the question or is compliant/non-compliant

in their answering as this means they don't have to process the question or upset the person asking the question;

- where there are multiple highly complex permanent disabilities, severe/profound disabilities and no changes in circumstances;
- where a current plan is in place is working well, where there is sufficient documentation from independent professionals that know the person with disability well;
- when it could be harmful to their wellbeing.
- *“Repeating the same information over and over again. Having to prove an intellectual disability with a stranger over and over - it stresses the individual and the 'professionals' are of varying capability skill. The NDIS recipient is reliant on who he gets on the day. I understand the need for assessment, however, if one is already in place from qualified psychologists, health professional - why the need (and cost to the government/tax payer) for a repeat?”*

The practice of repeated assessments to prove disability has been occurring in this sector for many decades and for those at the forefront of having to prove and re-prove a disability, it is a constant insult to the reality of disability. The NDIA have an opportunity to ensure this practice stays in the past and to reform the system to ensure this non-sensical practice does not continue into the future.

We want to ensure people with a developmental disability achieve an outcome that means they or their family member are not having to repeat their story or disability history many times over. Throughout the life of the NDIS to date, people with disability and their family members have gone through many assessments over the years and have many relatively up-to-date assessments already. Furthermore it is deemed as waste of time and taxpayer's money to make IAs compulsory for all participants, and as mentioned above it creates an unnecessary trauma and stress on the person with disability and their families when they are constantly trying to prove a lifelong disability.

Communications and accessibility

Any communication should be in Easy Read English and be available to be translated into multiple languages, including Braille and communication boards. The person with disability

should have the option to choose their preferred form of communication and have their accessibility needs taken into account. For example, face to face, phone, sms, Zoom etc.

The need for advocacy

We must highlight the absolute necessity of advocacy in any new NDIS process. The introduction of the NDIS created significant change in the sector and for people with disability and as a result, the current problems resulted in a greater need for independent disability advocacy.

Our families who have a person with a disability in their life have expressed shock that so much advocacy is required on their part. Families want to be heard in relation to these systemic issues, but are frustrated and exhausted, hence the need for independent advocacy's organisations.

On an individual level, our advocacy, representation and information has provided essential supports to enable people with disability (and their family representative) to fully participate in the NDIS and to be included in the community. At a systems level, this consultation is one of many where we, and other disability advocacy organisations, have provided submissions to State and Federal governments as well as directly to the National Disability Insurance Agency (NDIA).

Systemic advocacy can provide an alarm bell to warn where there are significant issues to enable the NDIA to respond to failures in the new IA process should it be implemented, prevent unnecessary cost, time wasting, and avoid problems before they blow up into preventable tragedies. Most importantly, it brings to the forefront the significant implications that current processes and practices are having directly on the people whom the system is there to support - the person with disability.

State and Federal Governments have a clear responsibility for ongoing funding to ensure that people with a disability will always be able to turn to local, independent advocate when they need them. Should the NDIA introduce the independent assessments, they must also provide extra funding for independent advocacy in order to support people with disability to navigate this new system, to assist those who "fall through the cracks" and to feedback to the NDIA any unintended consequences that may follow.

Family Advocacy calls on the NDIA, should a proposed Bill in relation to independent assessments be successful, to make a recommendation in the Bill that Federal, State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability, and that a boost of funding be specifically injected to advocates to help inform and support participants with the IA process.

Conclusion

This submission has clearly illustrated that people with disability and their family need the NDIS to hear that they are against the independent assessment process in its current form. The process needs to be a genuinely person-centred in its approach, valuing and respecting the lived experience of the person with disability.

As previously expressed, the need for advocacy has never been greater. Family Advocacy wants the NDIS to be a success. The NDIA must provide the due process in allowing for independent assessments to be challenged.

We hope the NDIA take note of our concerns, is prepared to listen to the feedback from families and their family member with a disability regarding the direct impact of the current policy on independent assessments and implement our recommendations.