



Submission on Access and Eligibility Policy with independent assessments AND Planning Policy for Personalised Budgets and Plan Flexibility

Noah's Ark Inc February 2021

## **About Noah's Ark**

Noah's Ark is a non-government organisation that was founded in 1971. We provide services to children with disabilities and other additional needs (0-12 years) and their families and carers. Noah's Ark provides National Disability Insurance Scheme (NDIS) services from 20 locations across metropolitan and regional Victoria, ACT and Albury NSW. Last year these programs reached over 2,500 families. We have been involved in NDIS from its commencement, in the Barwon and ACT trials. Noah's Ark is also involved in the Victorian Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. We provide training and resources nationally and internationally.

Noah's Ark has played a major role in the introduction of best practice services and support for inclusion in children's services for young children with a disability in Victoria and nationally. We have strong links to early childhood intervention researchers and fields internationally.

Noah's Ark welcomes the opportunity to comment on the Access and Eligibility Policy with independent assessments and Planning Policy for Personalised Budgets and Plan Flexibility Consultation papers in relation to children 7-14 years of age.

John Forster CEO

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## Introduction

The Planning Policy for Personalised Budgets and Plan Flexibility Consultation paper proposes major changes for participants over 7 years old in relation to independent assessments, access to the Scheme, participants personalised budget and plan flexibility, and changes to the planning process.

The proposal fundamentally changes the approach to individualised planning that was central to the establishment of the NDIS. Under the original model, decisions were made based on assessments provided by professionals working with the participant, a planning meeting that discussed goals and a budget built on achieving those goals. For most participants, access to the Scheme was based on having been in a State /Territory program before the NDIS or having a diagnosis which was on a List that granted access.

The proposed approach changes the focus from diagnosis and goals to a measure of functional capacity determined by an Independent Assessment (IA). This new approach effectively shifts responsibility for decisions about access and level of funding to the results of the IA. The formal decision is still made by the NDIA delegate, but it is based on the results of the IA. The decision made by the delegate can be appealed, but the IA cannot.

The aim appears to be to introduce a simple process for deciding access and funding allocations, which will replace the uncertainties of decisions made by NDIS delegates who are public servants. There has been criticism about variations in the decisions based on the decision makers understanding of disability and the influence of strong advocates.

The limitation of what is proposed is that people with a disability are in very different circumstances because of the impact of their disability and their desired level of social participation. In addition, bypassing professionals who know a person's capabilities because of working with them over to time to preferencing assessment results from 'independent' practitioners, using tools which are not designed for this use, is stepping into the unknown. It risks proposing a simple solution to a complex problem.

Noah's Ark endorses the eight principles of the Planning Policy, but we have concerns about several key issues outlined in the consultation paper, particularly in relation to Independent Assessments (IA).

# 1. Independent Assessments and access.

Noah's Ark supports the need for a more consistent and equitable approach to NDIS access and planning decisions and a focus on individual's functional capacity and the influence of environment, health and other individual factors outlined in the IA Framework (NDIS, 2020a). However, there are specific issues that must be considered in relation to children with disability and their families. Furthermore, an IA approach is contrary to what we know enables access to, and engagement with, services for families experiencing disadvantage.

IA is not a new idea and there is much to be learnt from others about the risks and benefits of such an approach. For example, independent doctors and clinical psychologists are contracted for the Disability Support Pension assessment, and the Australian Government utilises a national panel of assessors for Supported Employment assessments. In Victoria, the Department of Education and Training contracts an independent provider to conduct assessments for the Program for Students with a Disability. In the USA, many states use a vendor-based system for conducting independent assessments for early intervention (EI) services for young children with developmental delay/disability. Other US states ensure

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multi-disciplinary authentic, criterion and norm-referenced eligibility assessments, through the local EI service providers who meet practice standards and utilise an established suite of measures.

In addition to learning from the experience of state/territory, commonwealth and international approaches, Noah's Ark also recommends that the NDIS revisit the approach to IA through the lens of participants – in this instance, children and their families. The proposed approach has 6 steps within the access and eligibility process and a further 7 steps within the planning process. That is 13 steps before the family can begin to engage with service providers and implement the plan. This arduous process does not address the current challenges described in the consultation paper, including that the NDIS is confusing and frustrating and is too complex and difficult to navigate (NDIS, 2020b. p5).

One of the underlying issues related to implementation of IA is the unprecedented workforce pressures the sector is currently experiencing. There is a shortage of paediatric allied health practitioners and specialist teachers with the skills, knowledge, and experience to work effectively with children with a disability and their families. The development of the workforce for children does not appear to be a priority in the development of the NDIS. A workforce strategy that addresses the need for a comprehensive range of training options for those working in the field across pre-service, in-service, and postgraduate training is critical. These issues have been described for the broader workforce, but not the childhood sector, in the Joint Standing Committee on the NDIS Workforce Interim Report (Australian Government, 2020). Noah's Ark recommends the NDIS ensure issues related to the sector working with children and young people are addressed in the upcoming National Workforce Plan.

It is beyond the scope of this submission to comment in detail about the suite of assessments intended for use. We have read the IA Selection of Assessment Tools paper (NDIS 2020c) and the Addendum for children 1-6 years (NDIS, 2020d) and note there are some aspects to the proposed approach and suite of measures that not supported by research on eligibility assessment for children. These are described in some detail in our corresponding submission on the ECEI Reset.

Whilst some best practice elements have been addressed in the criteria in the IA Framework (NDIS 2020a), (including the need for suitable governance, future research, coverage of developmental domains, reliability, validity, and functional content with the chosen measures), there are additional criteria that should be considered. Macy & Bagnato (2010) offer a framework of standards for judging assessment in EI that include eight elements: Acceptability, Authenticity, Collaboration, Evidence, Multi-factors, Sensitivity, Universality and Utility. Two of the issues in these standards that we believe have not been given due consideration in the IA Framework include:

# a) Collaboration

Collaboration with parents of children being assessed for eligibility is obviously critically important. Collaboration with a multi-disciplinary team of professionals is also essential. Parents of children with a disability have typically been worrying about their child's development for a long time before they interact with the NDIS. They have sometimes been involved in screening assessments through their local Maternal and Child Health Nurse, medical assessments through the GP, developmental assessment with a Paediatrician, eligibility assessments for additional support at preschool and school, and/or specialist assessments with the audiologist or allied health practitioner. The approach proposed in the IA Framework is not clear about the extent to which information provided by these other

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professionals is either welcome or utilised. The synthesis of perspectives from parents and a range of professionals who know the child and family provides more robust information on which to make decisions about eligibility and planning.

## b) Multi-factors.

The IA Framework indicates that "Some people present with a degree of complexity that requires more in-depth deliberation than assessment findings can provide on their own. The complexity, nuances and intertwining factors may need to be examined more closely or may prompt more questions that need to be answered" (NDIS, 2020a. p.24). We suggest that children, by the very nature of their dependence on parents/caregivers, and the unpredictable nature of their developmental trajectory at this early stage of life, present with complexity that requires a more robust approach to assessment, including ecological data. This ecological approach includes collection of data across multiple methods, sources, settings, and occasions, and is described in Macy & Bagnato standards (2010) as 'multifactors'. Such an ecological approach to assessment should also include assessment of family support needs.

We recommend the NDIS develop an approach to improving early identification, referral and eligibility practices that is better integrated into the current service system, respects the role of families in their child's life, is in line with best practice guidelines and also ensures a more consistent and equitable approach to NDIS access and planning decisions. Established international frameworks might prove helpful (Dunst, Trivette, Appl, & Bagnato, 2004; Guralnick, 2019).

An integrated and developmental approach also requires further research to examine:

- The role of conventional and authentic assessments in determining eligibility.
- The degree to which conventional tests accomplish or do not accomplish eligibility and planning decisions.
- The development of more appropriate authentic measures that will enable the right children to receive the right support at the right time.

Finally, it is critical that children with disabilities have their life experiences valued in any decision-making process. Supporting children to develop their own agency is an important developmental process. Children with disabilities have the right to be recognised as 'experts in their own lives'. Any process that does not value the people who support a child with a disability, including their family and the professionals who work with them, is counterproductive to building the supportive community the child and the NDIS need to succeed.

# 2. Independent assessments, personalised budgets, and plan flexibility.

The proposed approach to IAs is that a person's functional capacity is assessed, considering environmental factors, informal supports, and individual circumstances. The results of the IA are proposed to determine the plan budget so that participants with similar levels of functioning and in similar contexts will get roughly the same amount of funding. What is not clear is how the results of the suite of assessments and individual circumstances translate to a budgetary figure. This requires clarification if the NDIS is to address one of the current challenges described in the consultation paper about the lack of transparency around how the NDIA makes decisions (NDIS, 2020b. p 5).

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It seems the NDIA's is recommending using IAs to develop a draft plan budget without conducting a planning meeting. Although these draft plan budgets are not finalised, the consultation paper lists only two circumstances where drafts can be changed: Accordingly. with personalised budgets largely determined by IAs, planning "conversations", as they are now known, will "no longer need to focus on the negotiation and agreement of each individual support. (NDIS, 2020b. p 14). Instead, the intent is that the meeting will primarily be focused on plan implementation. We are concerned about the restrictions placed on participants due to the limited circumstances in which plan budgets can be changed. We acknowledge that the recommendation outlined in the ECEI Reset paper (NDIS, 2020e).to create a distinct delegate/planner workforce that is exclusively focused on young children and their families may mitigate some of the issues for children and their families by ensuring more informed planners and delegates. However, the recommendation does not extend to children over the age of 7 years. Noah's Ark recommends that a distinct delegate/planner workforce focussed on children and young people aged 7-14 years be created and that they receive suitable training in areas such as child development, family centred practices, inclusion, and principles of best practice.

Planning conversations and 'check-ins' that support implementation are welcome. However, in order for families to understand how their funding can be spent and prepare them for the planning meeting, there needs to be a fundamental change in the way in which communications are produced and shared. Effective communications should aim to build the capacity of families to make informed decisions. This requires a far more comprehensive approach than planning conversations and 'check-ins'. The NDIS needs to work in partnership with organisations representing parents of children with disabilities, who are the essential stakeholders, to co-design accessible information. This should include disability organisations (e.g., CYDA) and organisations representing Aboriginal and Torres Strait Islander and Cultural and Linguistic Diverse communities.

## 3. Proposed NDIS planning process.

Noah's Ark welcomes removal of the 15 current support categories and the move to a simpler and more flexible approach. We recommend that the guidance to help families understand their plan should include individualised information form the NDIS planner and more generalised and accessible information through disability advocacy organisations and community organisations as described above.

We are eager to know how the 'fixed' funds will be operationalised for provider travel for EI supports given the recommendation in the ECEI reset paper to introduce a 'capacity building support in natural settings' item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings (NDIS, 2020e, p19). We recommend this be extended so that children and young people 7-18 years can also benefit from capacity building support in natural settings such as home and community programs.

We are also keen to understand the discord that is apparent given that goals do not factor into the draft budget, but participants are still expected to use their budgets to work towards defined goals.

We agree that plan variations to address issues such as adding funds for assistive technology, updating goals, moving funds from flexible to fixed or vice versa, and changing intervals for funding release should occur without an IA or plan review.

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We recommend that the Agency develops an approach to encouraging the child participant to be an active contributor to planning discussions and decisions and promote their capacity to have a say in decisions that are important to them. This is integral to their increasing independence and one of the core tenets of the Scheme – for participants to have choice and control.

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