



Association for
Children with a
Disability



Submission

Joint Standing Committee on the NDIS:
Specific issues for children and independent assessments

March 2021

ACD Victoria

ACD is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by and for families of children with disability.

Our vision is that children with disability and their families have the same rights and opportunities as all children and families.

We provide information, advocacy and support to more than 5,000 Victorian families a year.

Since the rollout of the NDIS we have supported thousands Victorian families to understand and access the NDIS with confidence. Their experiences inform this submission.

ACD Tasmania

The Association for Children with Disability (Tas) Inc. is a Tasmanian not-for-profit organisation. ACD Tas is a peer-led family organisation that provides information, advocacy, consultation and training, NDIS support coordination and peer support to families across Tasmania with children with disability.

Our mission is to provide community leadership and quality support options that improve participation and life outcomes. Our vision is that people with disability, their families and carers have equal opportunity to reach their potential and lead fulfilling lives.

Daily we engage with and work for more than 250 parents and carers and children and young people with disability (newborn to 25 years old) who require information, advocacy and support, including 208 participants of the NDIS. Their experiences inform this submission.

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We are available for questions or to attend a public hearing.

Contents

We have addressed the following terms of reference:

- Appropriateness of independent assessments for particular cohorts of people
- focus on children
- Implications of independent assessments for access to and eligibility for the NDIS
- Opportunities to review or challenge the outcomes of independent assessments
- Implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

Summary of recommendations

1. Establish independent assessments as an **option** for children accessing the NDIS
2. Do not roll out compulsory independent assessments to access the NDIS
3. If a family chooses the option of an independent assessment to gain access there must be a clear and transparent process to review and appeal the outcome
4. Retain current assessment and information gathering process to determine a child's NDIS Plan as this provides a more accurate and fuller picture of the reasonable and necessary support needs of the child and family to live a good life

Appropriateness of independent assessments for particular cohorts of people - focus on children

Assessments are already an important part of determining a child's NDIS Plan. Assessments are also used by therapists to monitor progress and set therapy goals and approaches.

The proposed independent assessments are to be repeated at different life stages and at least every five years. This means children will be the most assessed age-group as they have major developmental changes every year.

Families tell us and evidence supports that best practice when undertaking assessments with children¹ includes:

- A qualified multidisciplinary team who can make a holistic needs assessment using their knowledge of child development and assessment of a child's disability and function in different contexts.
- Therapists that the child knows and trusts.
- Incorporating assessments into capacity building therapy sessions to avoid over-assessing children.
- Ensuring assessments acknowledge when a child's progress is due to the sustained support they are receiving through their NDIS Plan, with the support continuing as a result.
- Understanding that a child may answer yes or no throughout the process without really understanding the question.
- Understanding that a child is not always aware of the support provided by their family to build their independence.

OBSERVATION

Compulsory independent assessments will have specific implications for children with disability, including over assessment.

"I cannot imagine replacing the specialist knowledge of the half a dozen professionals supporting my child with one assessment from someone who has just met them." Parent

"My child's progress is sometimes dependent on the supports remaining in place. I feel that assessments need to confirm this to avoid loss of supports." Parent

¹ Jack P. Shonkoff & Samuel J. Meisels, *Handbook of Early Childhood Intervention*, 2nd Edition, 2000

Independent assessments for children accessing the NDIS

Families tell us that accessing the NDIS is overwhelming, confusing and complex.

We know that for some children, particularly those in disadvantaged, regional and remote communities, the access process is a barrier to getting the support they need.

To access the NDIS families need to provide evidence in the form of reports and assessments on their child's developmental delay or disability. Many children are on public health waiting lists to get reports and assessments to support their access request. For those who cannot afford private therapists this can be a long wait.

However, many children have enough information and reports from their medical practitioners to support access. Many will also be able to source information and reports from allied health services they are already accessing.

RECOMMENDATION 1

Establish independent assessments as an **option** for children accessing the NDIS. For children aged 0 to 8 this should be undertaken by the Early Childhood Partner with early childhood and allied health qualifications. This option will help some children access support quicker.

"I do agree with independent assessments being used as an option for access. It took us so long to access the NDIS when my son was a baby, despite getting the paperwork before we left hospital. Getting your first Plan needs to be a smoother process that doesn't rely on getting reports you can't access, because you don't have an NDIS Plan!" Parent

RECOMMENDATION 2

Do not roll out compulsory independent assessments to access the NDIS.

"One of the reasons independent assessments won't work for my autistic child is that she often uses default answers such as 'yes' or 'no' when she has little idea about what the question means." Parent

Ability to review and appeal an independent assessment

Families who have successfully accessed the Scheme after multiple attempts tell us that if they **choose** the option of an independent assessment to gain access to the NDIS, it must be possible to **review and appeal** the outcome of the assessment.

Children must be able to reapply even if an initial assessment does not meet the access requirements. This is critical as there can be multiple reasons why a child does not meet access requirements, some of which may change over time; lack of, uncertain or incorrect diagnosis, developmental progress or deterioration.

The *Human Rights Convention on the Rights of the Child* and articles contained within it make it clear that parties must take all appropriate measures (including legislative and administrative) to ensure that a child is not discriminated against or punished on the basis of disability. A right to review and appeal will provide an avenue to ensure that this does not occur.

RECOMMENDATION 3

If a family chooses the option of an independent assessment to gain access there must be a clear and transparent process to review and appeal the outcome. The child must also be able to re-apply if needed. This will ensure procedural fairness.

Independent assessments and getting the right NDIS Plan for children

There are significant risks with independent assessments determining a child's NDIS Plan and what will be funded as reasonable and necessary supports.

Families tell us, no single assessment can capture the complexity of a child's disability and their support needs.

Additionally, children are part of a family and the proposed assessments do not assess the level of informal supports, family capacity or family complexity that exists.

Currently a child's NDIS Plan is informed by a range of information, including:

1. Assessments by therapists, e.g. speech therapist, occupational therapist.
2. Reports from medical practitioners.
3. Reports from child and family workers that may be involved with the family. This is critical for vulnerable families experiencing complex situations.
4. Carer Statement from the family.
5. Participant Statement from the child.
6. For children aged 0–7 the Pedi-CAT assessment, undertaken with families by the Early Childhood Partner in the planning meeting.
7. The goals of the child and family.
8. Conversation in the planning meeting.

While this information and document gathering is time consuming for families and their supporters, it is a process that provides evidence of a child's support needs and cannot be replaced by a one-off assessment.

RECOMMENDATION 4

Retain current assessment and information gathering process to determine a child's NDIS Plan, as this provides a more accurate and fuller picture of the reasonable and necessary support needs of the child and family to live a good life.