



**Children and Young People  
with Disability Australia**

# **Improving the NDIS for children and young people with disability and their families**

**Children and Young People with Disability Australia Submission – October 2019**

**Establishing a Participant Service Guarantee and removing legislative red tape  
review**

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## Executive Summary

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children and young people with disability, and advocacy and community organisations.

CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia.

This submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability about their NDIS experience. It is also informed by our 2019 National Education Survey conducted in August and September 2019 of 505 families and students with disability.

While CYDA supports the National Disability Insurance Scheme (NDIS), the implementation has been plagued by implementation challenges. Therefore we welcome the establishment of the NDIS Participant Service Guarantee and the review of the current legislation.

Even before entering the scheme, families of children and young with disability encounter challenges with the NDIS eligibility criteria and the difficulty in obtaining medical diagnostic reports and assessments to prove the child's disability. This provides significant costs and stress to families, and inequitable access for children living in families experiencing poverty or hardship. Many find it hard to access to the scheme without support or advocacy services. Families are also concerned their child only receives support for what is considered the "primary disability" rather than support for the full spectrum of needs

The information about accessing the scheme, and throughout the planning and implementation process has been confused. Families are unclear on what the scheme can and cannot fund and are not supported to access services and supports outside the NDIS when these are not included in the NDIS plan. The interface issue with the NDIS and other systems such as health and education need to be urgently resolved by the NDIA and state and territory governments.

During the planning stage families reported the NDIS was not designed for children and there is a lack of family centred practice. NDIS plans consider children and young people in isolation from their families despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments. Families are denied support and services as considered "parental responsibility, and there is a push to medicalise the supports in the plan rather than consider the natural environments and supports in the community which promote the wellbeing and development of children and young people.

no having access to the NDIS draft prior approval and the need of face to face discussions as telephone meeting not always appropriate to engage young people and children with disability and their families /caregivers. Pre-planning support for all children and young person with disability and their families is an urgent need to improve NDIS plans and participants outcomes.

The lack of knowledge by the National Disability Insurance Agency (NDIA), Early Childhood Early Intervention (ECEI) partners and Local Area Coordinators (LACs) about disability, development transitions for children and young people, and family-centred practice was criticised by families. They also need to work with multiple staff rather than having a one single point of contact throughout the planning process, which proves challenging.

The emergence of thin markets, long wait lists and little choice of service providers in local communities is providing challenges and this issue is more pronounced for families living in regional, remote or rural areas as well as families with culturally and linguistic diverse backgrounds.

Families also reported that once the NDIS plan is approved don't know what is the next step, how to use the funds or to find and compare providers and resulted in underspending and underutilisation of plans.

The review and appeal process has also been identified as problematic including the language used by the NDIA staff and its partners which is confusing and unclear. Families reported issues with the lack of clear timeframes when requesting a review decision and the stress and financial pressure to cover the services while waiting for a review decisions.

We make a number of recommendations for improving the NDIS for children and young people with disability for the Participant Service Guarantee including three new principles, specifically for children and young people with disability: *early intervention*, *family-centred practice* and *evidence-based practice*. We also recommend two other principles for all participants which are *accountable* and *consistency*.

A summary of the major legislative changes recommended to the National Disability Insurance Scheme (NDIS) Act 2013 are:

- Amend the sections 25 and 26 to ensure that pre-existing diagnostic/assessment information can be used and to ensure children with disability and developmental risks who will benefit from early intervention can access the scheme.
- Amend Section 34 particularly subsection (e), (g), and (h).
- Amend Section 37 to enable review of plan before finalisation and allow 20 working days to request changes after plan notification.
- Amend Section 100 subsection (6) including a timeframe of 20 working days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply.

## Recommendations

### **Review the NDIS for children and young people with disability to ensure evidence-based practice**

- Conduct a review of the NDIS for children and young people with disability aged up to 25 in consultation and co-design with families, young people with disability, advocates, researchers and Aboriginal and Torres Strait Islander and Culturally and linguistically diverse stakeholders
- Ensure NDIA partners and staff are trained fully in family-centred practice
- Develop tools and resources for families so they feel empowered in enacting evidence-based choice and control on behalf of their child

### **Streamline Access to the NDIS**

- The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts
- Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed
- Provide interim plans for families of children from 0 to 6 years old while awaiting the full suite of diagnostic evidence needed to prove eligibility.
- The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability
- Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

### **Improve information about the NDIS across access, planning and plan implementation**

- Simplify the terminology used across the NDIS scheme, using easy simple keywords
- Develop consistent and accurate information spanning access, planning and plan implementation
- The NDIA continually monitor the information needs of the current and prospective NDIS participants and their families/caregivers and provide accessible information
- Amend NDIS Act 2013 Section 34, particularly subsections (e), (g) and (h)
- Develop resources about providers, their responsibilities and alternatives for when the families of children and young people with disability experience thin markets

### **Improve the NDIS planning process**

- Offer pre planning support families of children and young people with disability to improve the quality of NDIS plans and outcomes
- The NDIS Act 2013 (Section 37) be amended to enable review of plans before finalisation and allow 20 working days to request changes after draft plan notification

### **Build the capability of NDIS, ECEI and LAC's planners**

- Require NDIA planners, LAC and ECEI workforces to receive training in family-centred practice, child and youth development and empowerment

- Provide regular and transparent reporting on families of children with disability and NDIS participants' satisfaction with the planning process

#### **Address thin markets and underutilisation of plans**

- Provide support coordination for all children and young people with disability during implementation of NDIS plan.
- The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time
- The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports
- The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services

#### **Reform the NDIS internal reviews and appeals process**

- Amend NDIS Act 2013 Section 100 subsection (6) including a timeframe of 20 days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply
- The NDIA inform participants and their families/caregivers through a written communication about their NDIS funding while the review of the reviewable decision is in course
- Review and simplify NDIS terminology related to reviews
- Hold NDIS reviews face to face (when possible) enabling participants to have an advocate at the review
- Reform the AAT appeals process, and resolve issues earlier to prevent escalation to the AAT

#### **Address NDIS interface issues**

- Increase transparency about the work of the Disability Reform Council and the NDIA to address NDIS interface issues and monitor progress over time
- Consider the legislative changes that may be required to clarify roles and responsibilities between the NDIS and other government funded services
- The NDIA and state and territory governments provide accessible information to current and prospective NDIS participants about what the NDIS will fund, and where people can access other services

## Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 including young people with disability, families and caregivers of children and young people with disability, advocacy and community organisations.

CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia and undertakes the following to achieve its purpose:

- Listening and responding to the voices and experiences of children and young people with disability.
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community.
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability.
- Informing children and young people with disability, their families and care givers about their citizenship rights and entitlements.
- Celebrating the successes and achievements of children and young people with disability.

CYDA welcomes this opportunity to provide a submission to Mr David Tune AO PSM, Expert Reviewer for the establishment of the NDIS Participant Service Guarantee and removal of legislative red tape.

This submission is informed by our members and results from a national NDIS survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability about their experiences of the NDIS. It is also informed by our 2019 National Education Survey conducted in August and September 2019 of 505 families and students with disability.

This submission makes a number of recommendations to improve the operation of the NDIS for children and young people with disability along with what needs to be included in the Participant Service Guarantee to ensure children and young people with disability have evidence-based supports.

## Review the NDIS for children and young people with disability to ensure evidence-based practice

### Recommendations

Conduct a review of the NDIS for children and young people with disability aged up to 25 in consultation and co-design with families, young people with disability, advocates, researchers, Aboriginal and Torres Strait Islander and culturally and linguistically diverse stakeholders

Ensure NDIA partners and staff are trained fully in family-centred practice

Develop tools and resources for families so they feel empowered in enacting evidence-based choice and control on behalf of their child

The importance early childhood, adolescence and early adulthood for lifelong inclusion, employment, economic independence and wellbeing is well known. The NDIS was essentially initiated in an adult paradigm, and then adapted to fit the context of children and young people with disability.

The development of children and young people with disability needs to be considered as a normal process, just like it is for children without disability, and the importance of the home environment, along with other educational and community environments cannot be underestimated. The same general features of development and learning apply to children with disability to those without.

Children with disability, like all children, develop through their relationships with the important people in their lives. Sensitive and responsive caregiving is a requirement for the healthy neurophysiological, physical and psychological development of a child. The attachments that children form with parents and caregivers create the central foundation from which the brain develops. Children's ongoing learning depends upon having repeated opportunities to practice developmentally appropriate skills in everyday situations with support ('scaffolding') from attuned and responsive caregivers.<sup>1</sup>

The family environment influences the development and behaviour of children with intellectual and developmental disability and experience of having a child with disability almost inevitably has a significant impact on the family and they also need support. However the current NDIS current frameworks consider the child or young person in isolation of their families and the important role they provide in supporting their child to develop, but also in providing caring responsibilities.

The Early Childhood Early Intervention (ECEI) pathway has been plagued with problems from a process and from an evidence-based practice perspective. The research tells us that family-centred practice is the 'gold standard' of early intervention, however families surveyed by CDYA report that the needs of the family to provide a safe, supportive and enriching environment is not considered in NDIS processes

"The ECEI planners do not provide a family model considering simply the child and do not consider the importance of prompt early intervention" Family of a child aged 4-6 years, metropolitan Queensland

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<sup>1</sup> Department of Education and Training (2010) Early childhood intervention reform project <https://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf>



Additionally, families report that they are offered clinically based therapy services in their plans which are based on traditional models of one-on-one support for the child with disability, as opposed to building the capacity of the family to support the development of the child, and to participate in universal services like preschool, education and other community environments.

“This year we have not been able to access support for any social community inclusion for our eldest son with autism. NDIS deemed it parental responsibility. We cannot take him to social events like a sport group with someone available to solely focus on him. He has to have a support person with him to guide him through the difficulties that arise from social difficulties.”  
Family, with 2 children in the NDIS, metropolitan South Australia

The notion of choice and control is a foundational underpinning of the NDIS, however families new to disability report not being able to understand what is best to include in their child’s plans. There is the need for capacity building for families to understand what is important to include in their child’s plan that will help the child in their learning and development, alongside the family’s support needs.

CYDA organisational members report to us that evidence-based practice in early childhood intervention has gone backwards since the commencement of the rollout. This includes a loss of expertise from the sector, including trans-disciplinary practice which is a key feature of evidence-based early childhood intervention. They also report that private providers have a vested interest in maintaining individual clinical based interventions with the child, which are cheaper to provide, rather than home-based capacity building for the whole family.

The transition for children following participation in the ECEI pathway is also vexed. While the evidence about brain development shows the importance of the early years up until 25 as a critical window for early intervention, to only have an early intervention pathway that goes to aged six is problematic. This cut-off also comes at a time when one of the most critical transitions happens when children transition to school. CYDA members report that these transitions have deteriorated since the introduction of the NDIS as there are often gaps between when the child start school and when they receive the necessary adjustments at school. Before the NDIS, early childhood intervention providers often assisted families negotiate this difficult transition. Additionally many children do not get a formal diagnosis until after six as they may have a cluster of developmental issues that are yet to have a formal diagnosis. Therefore limiting early intervention children aged up to 6 means many will miss out on important support.

Many families tell CYDA they need to go through a stressful process of proving their child still has a disability to continue to be eligible for the NDIS, which is covered in later sections of this submission.

In order for the NDIS to operate as a true insurance scheme, where the lifetime costs are smaller because children and young people with disability have been supported in their development and learning, we recommend a complete review of the NDIS for children and young people under the age of 25. This review needs to consider all the stages of development from early childhood, adolescence and transition to adulthood to insure the NDIS is fit for purpose. This must be informed by the evidence base and deep consultation with families, young people with disability, advocates and researchers.

## Streamline access to the NDIS

### Recommendations

The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts

Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed

Provide interim plans for families of children from 0 to 6 years old while awaiting the full suite of diagnostic evidence needed to prove eligibility.

The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability

Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

Our NDIS survey found 50% of families / caregivers of children with disability had barriers to accessing the NDIS<sup>2</sup>.

This included challenges in sourcing the required evidence and diagnostic assessments, difficulties understanding the scheme and unclear information about the NDIS.

The burden on families to provide the diagnostic evidence to prove eligibility to the NDIS provides a major barrier for participation. Families reported the NDIA does not allow the use of previous diagnostic assessments as valid evidence. This is a major hurdle for families of children and young people with disability to cover the costs of medical expenses. For example the Autism CRC found that the cost of accessing private autism assessment in Australia could be up to \$2,750 when accessing private services with the median cost being \$580<sup>3</sup>.

It is well known that families facing poverty and disadvantage face significant barriers to accessing services generally and there is under-diagnosis of disability. This makes it harder for children and young people with disability living in these families to receive services to support their disability and be included in mainstream services such as education and health, let alone secure the assessments required to prove eligibility to the NDIS.

The NDIA needs to review its approach to 'evidence for eligibility' to ensure it does not provide major barriers to children and young people with disability who should be eligible but are locked out because of cost, limited access to health and allied health services or existing evidence is not considered as adequate.

It is also important to acknowledge that some children may have more than one disability or have complex needs. Therefore NDIS funding should not be limited to primary disability diagnosis as this

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<sup>2</sup> CYDA NDIS Survey 2019

<sup>3</sup> Taylor, L et al 2016. Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards? Autism Co-operative Research Centre, Brisbane.

will disadvantage participants and their families to access the right support and services to cover all their needs.

“Deafblind was not recognised as a disability originally had deaf as primary vision as secondary took 6 months to fight this” Family of a young person with disability aged 18-25 years, metropolitan NSW

For 17.1% of CYDA survey respondents they reported wait times to access the scheme were extremely long, with many waiting more than 12 months to enter the NDIS.

“It took twelve months from applying to receiving funding. Early in in the piece someone made an error and deemed I had not submitted all the information. I spent two hours at month three on the phone with them while they clarified it had been their mistake and actually the application could proceed. During this time they did not write or communicate to me that they believed there had been an error I just had to call repeatedly to ask them what was going on. After this initial confusion was sorted it took another 9 months to progress to being funded. Every time I called I was told it was my fault as I had made a mistake initially (despite it being clarified that I hadn’t). During these 9 months I had a 10 year old child that was suicidal.” Family of a child aged 10-12 years, Metropolitan Victoria

“It took about 9 months from the time of eligibility confirmation to get plan 1” Family of a child aged 7-9 years, Metropolitan NSW

“Wait time was ridiculous. 14 months from the time our referral was put in to the time i received the phone call we had received funding. Then another 2months to get a plan into place.” Family of a child aged 4-6 years, Regional NSW.

In June 2019 the Minister for the National Disability Insurance Scheme (NDIS), Stuart Robert announced changes to decrease delays of children with disability entering the scheme including a six month interim plan of \$10,000 for children who are eligible for the NDIS, are not categorised as complex and in a risk of waiting more than 50 days to get a plan<sup>4</sup> and since mid-August the NDIA staff is calling families who have waited more than 50 days since receiving access decision to discuss interim plans<sup>5</sup>. While we welcome this initiative, it does not address the challenge of families who are struggling to access the medical evidence to prove eligibility.

In the early years children may experience developmental risks but may not yet have a formal diagnosis and this disadvantages them and their families from receiving early intervention support that they may have received under previous state and territory systems.

In order to overcome these issues CYDA recommends amending the sections 25 and 26 of the NDIS Act to ensure that pre-existing diagnostic/assessment information can be used and to ensure children with developmental risks who will benefit from early intervention can access the scheme.

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<sup>4</sup> NDIS. Children to get faster access to NDIS supports. <https://www.ndis.gov.au/news/2990-children-get-faster-access-ndis-supports>

<sup>5</sup> NDIS. Next steps to address wait times in accessing Early Childhood Early Intervention. <https://www.ndis.gov.au/news/3491-next-steps-address-wait-times-accessing-early-childhood-early-intervention>

Another challenge identified by families of children and young people with disability is that the ECEI, LAC's or Planners disregarding the evidence provided due to lack of understanding and families needing to explain several times the same information.

"Finding a location to meet and travel First planner had no experience with disability and was completely overwhelmed by scope of plan and amount supporting documentation provided. Every time we do a plan review, we have to go over everything again which is frustrating for my son and me" Family of a child aged 10-12 years, Metropolitan VIC

Automatic access to the NDIS for children and young people with disability or with developmental delay who were receiving funds prior the scheme from Commonwealth, States or Territories should be within 20 working days. CYDA confirms through its NDIS survey that many were experiencing delays.

"We were referred by DHS. It took ages and was very process intensive." Family of a child aged 10-12 years, regional VIC.

"We're told we might be transitioning early and then DHHS changed their mind. DHHS also promised \$3k+ of consulting to assist the process and then withdrew that offer without explanation." Family of young person aged 18-25 years, metropolitan VIC

The NDIS Act 2013 currently does not have a provision to respond to families with children and young people with disability in crisis, for example those experiencing family violence, the death of parents/primary carer, migrants with a refugee status, families in temporary accommodation. In these urgent situations the access decision to enter the NDIS should be within five working days.

Advocacy and support services for families are at breaking point since the introduction of the NDIS, and many families find it difficult to access these services to assist them negotiate the NDIS access process. The NDIS has been implemented without increased funding to Australian Government National Disability Advocacy Program (NDAP) funded services or state and territory funded advocacy services, with some jurisdictions also withdrawing funding. Additionally information services previously funded by state and territory jurisdictions have lost disability specific information funding, which has not been picked up by the Information Linkages and Capacity Building (ILC) grant rounds.

## Improve information about the NDIS across access, planning and plan implementation

### Recommendations

Simplify the terminology used across the NDIS scheme, using easy simple keywords

Develop consistent and accurate information spanning access, planning and plan implementation

The NDIA continually monitor the information needs of the current and prospective NDIS participants and their families/caregivers and provide accessible information

Amend NDIS Act 2013 Section 34, particularly subsection (e), (g) and (h)

Develop resources about providers, their responsibilities and alternatives for when the families of children and young people with disability experience thin markets

CYDA is concerned that information about access to the scheme for families of children and young people with disability very limited and in general not clear for prospective and current NDIS participants. This is particularly challenging for those living in regional, rural or remote areas. Access to information in different formats such as online, phone advice, hard copy, Easy English, information in different languages, videos with captioning, need to be part of the accessibility package. At the first point of contact, the NDIA, ECEI or LAC needs to verify the family or young person with disability understand the access process and how to navigate their NDIS journey. This could include asking family/caregivers of children and young people with disability after their first meeting how they want to receive the information, whether they want to bring informal support such as other family members or friends, or need formal support such individual advocacy service or from organisations with ILC grants their local area and connect with them.

15.7% of CYDA NDIS survey respondents experience challenges applying for the NDIS due to lack of information, not knowing the support and services covered by NDIS, how it works, how to start the process or to develop a plan.

“Inconsistency in funding, Lack of communication Lack of clarity on what is/isn’t included and why” Family of a child aged 0-3 years, Metropolitan NSW

“A lot of confusion about what I needed to have.” Family of a child aged 16-18 years, Metropolitan VIC

“I wanted to self-manage the first year of NDIS for both my disabled children BUT the NDIS and the LAC staff could NOT tell me how to do this. An entire lever arch file later (a BIG lever arch file) and I gave up on the NDIS entirely. I did not spend a cent that year as I could not figure out how to.” Family of a child aged 10-12 years, regional QLD

The lack of accessible information was reported during the planning stage where families experienced poor quality plans and outcomes for the child or young person with disability. Families said planners provided incorrect information, they had to deal with multiple staff, and there was inconsistency of information and a diminishing of family and participant's choice and control. This generated financial burden and stress for families.

The terminology used by the NDIA staff and allied partners is not clear with much use of jargon and hence there is a need to simplify the NDIS terminology. Further information should also be given to what is ‘reasonable and necessary’ under the NDIS Act. Therefore CYDA recommends

amendments to Section 34 of the NDIS Act 2013 particularly subsection: “ (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide; (g) the support is not prescribed by the National Disability Insurance Scheme rules as a support that will not be funded or provided under the National Disability Insurance Scheme and (h) the funding of the support complies with the methods or criteria (if any) prescribed by the National Disability Insurance Scheme rules for deciding the reasonable and necessary supports that will be funded under the National Disability Insurance Scheme.”<sup>6</sup>.

The literal interpretation of sub-section (e) in section 34 of the NDIS Act 2013 has disadvantaged families of children and young people with disability and a refusal of funds for services or support deemed a “normal parental responsibility”. Families are the experts of what the child or young person with disability needs so their input and information is important for the funding allocation of support and services. This also goes against the gold-standard approach of family-centred practice

“Caused a lot of stress trying to get across the difference between caring for my son and additional time required because of his disability vs what NDIS considered parental responsibility” Family of a child aged 0-3, Regional QLD

There is a complete lack of information about how to navigate the NDIS service system including providers and support coordination services and how to assess the quality of the provider. This more pronounced for families living in regional, rural or remote areas with few registered providers or providers with long waiting lists.

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<sup>6</sup> NDIS Act 2013, Section 34 <https://www.legislation.gov.au/Details/C2013A00020>



## Improve the NDIS planning process

### Recommendations

Offer pre planning support families of children and young people with disability to improve the quality of NDIS plans and outcomes

The NDIS Act 2013 (Section 37) be amended to enable review of plans before finalisation and allow 20 working days to request changes after draft plan notification

CYDA NDIS Survey results show that 71% of young people and family/caregivers of children and young people with disability experienced difficulties with the NDIS planning process.

Families, as the key caregivers of children and young people with disability, report they are invisible in the scheme. They say plans are being developed which fail to recognise the important role families' play and the importance of community supports which will enrich the child and young person's life.

NDIA staff and ECEI and LAC partners are said to prioritise individual therapies in plans rather than consider all the environments children and young people need to support their development and wellbeing. The majority of learning for children and young people occurs in their home, community and educational environments. Therefore individual therapy cannot be a major driver of development – what drives development is children's meaningful participation in everyday activities and environments.<sup>7</sup> The reliance on medical models, rather than natural supports for children and young people and their families was criticised by our survey respondents.

"Denied support worker hours, denied riding for the disabled, denied help with support workers for after school hour care. Planner didn't know what after school care was! All occurred at planning meeting." Family of a child aged 4-6 years, regional Queensland

"Respite was difficult to get as "parental responsibility" kept getting quoted, even though the single parent was not able to do these parental responsibility due to physical & mental health issues". Family of a child 10-12 year old child, metropolitan NSW

"I would still like more services around inclusion and getting my son out in the broader community. There is a lot of camps and programs for people with disabilities but not a lot of stuff that intersects into mainstream groups." Family of a child aged 10-12 years, metropolitan Melbourne

The other significant challenge for families with children and young people with disability is being unable to work because of the care requirements. They report that they would like to work, but are unable to, because caring for their child is seen as their "parental" responsibility. There is little understanding of the higher-level support provided by families to meet their child's everyday needs. Forcing families to live on low incomes or poverty because they are unable to work will not ultimately assist the child or young person live a good life.

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<sup>7</sup> Centre for Community Child Health (2011). DEECD Early Childhood Intervention Reform Project: Revised Literature Review. Melbourne, Victoria: Department of Education and Early Childhood Development. <https://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf>

Our survey also confirms families experience long delays of up to 12 or 18 months to receive NDIS funding approval. Some of the issues mentioned were administrative mistakes by NDIA staff or allied partners and high staff turnover.

“Rollout was 1st Oct 2019 Brotherhood of St Laurence set up office 15 Feb 3 month wait from planning meeting to implementation, basically poor advocacy” Family of a young person aged 18-25 years, Metropolitan VIC

“Unable to access NDIS system for 4 months due to incorrect key code due to their typing a birthday in incorrectly then finding they had marked account 'other' not 'mother' so unable to access anything.” Family of a child aged 13-15 years, Regional QLD

Families reported not being informed about what to bring to planning meetings or being overwhelmed by collecting the evidence and reports for planning meetings. There were also reports of plans having supports that were not requested, or underfunding of plans. Planner capability was cited as a key challenge.

It has been found that the quality of NDIS plans relies on the two factors: the knowledge and experience of the NDIA staff or allied partners and the level of advocacy support families and participant receive before and during the planning process<sup>8</sup>. To overcome this issue CYDA recommends that the NDIA should provide pre-planning support to all participants and their families.

Currently families of children and young people with disability do not have access to the draft plan and only see what is included in the plan once it is approved. Many respondents stated that they hadn't been provided with a formal communication or explanation about when a service or support is underfunded or unfunded. CYDA recommends to amend the NDIS Act 2013 Section 37 and add access to draft plans giving 20 working days to participants and their families after notification to request changes.

Families of children and young people with disability believed they had to liaise with too many NDIS staff during planning process and no explanation when the ECEI, LAC's or Planner leave the organisation or is moved to another team. The turnover of staff means there is no continuity in information provision and it is reported there is variable levels of knowledge and expertise about disability which impacts on families.

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<sup>8</sup> Joint Standing Committee on the National Disability Insurance Scheme: Transitional arrangements for the NDIS, page 39. 15 February 2018.

[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/Transition/Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Transition/Report)



## Build the capability of NDIA, ECEI and LAC's planners.

### Recommendations

Require NDIA planners, LAC and ECEI workforces to receive training in family-centred practice, child and youth development and empowerment

Provide regular and transparent reporting on families of children with disability and NDIS participants' satisfaction with the planning process

The respondents to CYDA NDIS survey reported planners did not have the experience, knowledge or qualifications relevant to the role and hence the plans were not tailored to the needs of children and young people with disability. The family/caregivers said the support for carers is not included in the plans and there are funding shortfalls. The lack of family-centred practice will mean children and young people with disability to obtain the right services and support.

"Planners do not have the qualifications or necessary experience to deal with PWD who have complex needs" Family of a child 13-15 years, regional VIC

"Planner was inattentive, lack of knowledge, read from a script, did not try to understand, was rude, provided a plan that was less than previous supports from DSC, provide no core support, despite full documentation, would not discuss her qualification, would not review plan or discuss or explain reason the way the way was given, had to cancel bonded core support workers whilst in review, lots a year of rapport building and enabling transition to school, (school refusal due anxiety disorder) required 4 months to rebuild, Planner unaware of autism presentation in females or PDA, was unaware of the Ehlers DANLOS/Marfan's, not included in diagnosis, so no physical supports provided, unable to contact NDIS, different people, different stories/advice, Review process STRESSFUL, the language used is difficult to understand, staff twisted enquiry in knots and creates stress for the career, Poor understanding of mental health impact on careers caring for those with MENTAL health issues, respite not provided, not understanding of financial impact when careers unable to obtain employment, when caring for teen with mental issues 24/7" Family of a child 13-15 years, metropolitan WA

Another difficulty mentioned by our survey respondents was the lack of consistency between planners leading to underfunding through not having enough knowledge, ignoring relevant information or misinterpreting medical records.

NDIS planners, LAC's and ECEI staff need to be trained in and attuned to the individual circumstances of the children and young people with disability and their families. This includes families in crisis, parents with a disability, CALD families, families experiencing family violence, children living in out of home care, Aboriginal and Torres Strait Islander families, grandparents raising children, families living in rural or remote areas. NDIS plans and support required must reflect and acknowledge all these circumstances.

Staff knowledge is also required in child and adolescent development and transition to adulthood as the needs and goals will change for children and young people with disability and their families over time and they will need guidance throughout these transitions.

## Address thin markets and underutilisation of plans

### Recommendations

Provide support coordination for all children and young people with disability during implementation of NDIS plan.

The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time

The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports

The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services

There were 67% of CYDA NDIS survey respondents who had some difficulty or not been able to access the right services and supports needed.

Challenges in accessing the right services and supports for children and young people with disability were present across all geographic locations, as outlined in the following table. However it was more difficult in regional and rural and remote locations.

Location	Number of survey respondents	% with barriers to accessing the right services and support
Metropolitan	121	63%
Regional	52	71%
Rural and remote	16	87%

There were multiple barriers to accessing the right services and support for children and young people with disability as outlined in the following table

Barriers to accessing supports and services	Number
Not enough services available in the area	37
Plan doesn't allow for services needed	25
Waiting lists	23
Support coordination challenges including difficulty in navigating services, time and self-management	16
Workforce capability	15
Equipment and assistive technology	11
Accessibility of the service including flexibility and location	8

Cost of services and funding shortfall between NDIS plan and services and supports needed	8
Respite and family support not being available/funded	8
Interface issues with other systems	4
Other/unspecified	17

Not having the right services and availability in the area plus the plan not allowing for the services needed were reported as the top issues for children and young people with disability.

“There is a severe shortage of therapist, support workers, treating doctors and long wait lists. Even when signed up with a service, there is a shortage of available appointments. We have accepted, in desperation, untrained and (previously) unacceptable support workers just to have another pair of hands on board. All the wonderful skill development that we previously could work on has now become purely survival.” Family, young person aged 18-25 years, metropolitan New South Wales

Other challenges included the long waiting lists for services, lack of service availability and no services to choose from especially for families with CALD background where language is a top barrier. These issues decrease the choice and control by NDIS participants and their families.

“Not a lot of support in my area. Support workers/therapists come from outside the area and therefore add transport costs. Have to go to review to become plan/self-managed so I can find support networks.” Family of a young person aged 16-18 years, metropolitan Victoria

“Long waiting list for therapists. No consistency in support workers that change every fortnight.” Family of a child aged 10-12 years, metropolitan New South Wales

“Living in the western suburbs there is a dearth of services and supports. So even when one has a plan, it's difficult to find suitable qualified and experienced professionals to hire”, Family of a child aged 10-12 years, metropolitan Victoria

Respondents to the survey provided multiple examples of difficulty in accessing Assistive Technology (AT) and equipment which is essential for children and young people children’s changing needs, for example maintaining or updating the AT or equipment. It is not clear for families the criteria to access AT or funds under the Capital Supports Budget.

“Electric wheelchair required new batteries and charger, but because this wasn't included in the original plan, we had to wait until the new plan was in place to get this item as the provider wouldn't let us pay for them outside of the NDIS.” Family of a young person aged 18-25 years, Australian Capital Territory

“It took over twelve months to get new ankle foot orthotics for my daughter - I had to go to my local member of parliament I was so frustrated. My daughter was 6 years old and had been wearing them since she was 3 years old. I also had to fight for a budget in her new plan for a replacement set - god forbid she has the audacity to grow in the next 12 months!! Planners are too 'insurance' focused; I am trying to build my daughters capacity NOW so she is a more capable adult - but all the planners can see is trying to save money.” Family of a child aged 7-9 years, regional Victoria”

Waiting over 18 months for essential equipment for my son's physical disability has been a joke. He has also been in a too small of wheelchair for two years and NDIS kept fobbing everything off. Thankfully now the new wheelchair is being made, but two years of my son being in a too small of wheelchair has caused physical pain and issues and increased anxiety. NDIS is supposed to help the participant, not make them worse"  
Family of a child aged 10-12 years regional Queensland

CYDA recommends to have a time frame of 30 days to approve Assistive Technology (AT) and equipment. There should also be funding for maintenance and repair of AT and equipment so families don't need to request a review of their plan to enable this.

Our NDIS survey participants tell us there is a mix of experiences depending on whether the child or young person with disability is on their second, third or fourth NDIS plans. Some families reported improvements and others were disadvantaged due to funding cuts or a service or support approved in first plan not included in the next plan without explanation. It was also identified in the transition from 6 to 7 years old children the funds were drastically cut. Families also confirm the collection of evidence and assessment to justify the funding increase the level of stress from families.

Access to support coordination is another challenge in the implementation process. Many families of are not aware how to start using the funds once the plan is approved, where to find support workers and what to ask to providers to compare services. This issue was confirmed in the last COAG Disability Reform Council Quarterly Report where only 42% of participants received funding support coordination and 22% of participants who received an approved NDIS plan were uncertain of what to do next or where to go for further assistance<sup>9</sup>. CYDA believes that support coordination should be guaranteed to all children and young people with disability. This will help address the issue of underutilisation of plans.

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<sup>9</sup> COAG Disability Reform Council Quarterly Report June 2019. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

## Reform the NDIS internal reviews and appeals process

### Recommendations

Amend NDIS Act 2013 Section 100 subsection (6) including a timeframe of 20 days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply

The NDIA inform participants and their families/caregivers through a written communication about their NDIS funding while the review of the reviewable decision is in course

Review and simplify NDIS terminology related to reviews

Hold NDIS reviews face to face (when possible) enabling participants to have an advocate at the review

Reform the AAT appeals process, and resolve issues earlier to prevent escalation to the AAT

The lack of opportunity to review the draft plans increases the number of internal reviews of NDIS decisions. Families state long waits for reviews without timeframes for a response from the NDIA is causing gaps in support, services and equipment for children and young people. The NDIS Act 2013 (section 100) regarding review of reviewable decisions, literal (2) states that the NDIS participant must make a request for review within the three months after receiving the notice, in literal (6) states the reviewer must, as soon as reasonably practicable, make a decision<sup>10</sup>. However, the long waiting periods for a review discourages families from seeking a review. CYDA recommends Section 100 literal (6) is amended to add a timeframe of 20 working days for the reviewer to make a decision as long as the reviewer has all the evidence to decide, or in the event of requesting more information an extension of 28 days will apply.

Families of children and young people with disability are neither informed about what happens with the funding while the review of the reviewable decision is underway. Therefore CYDA recommends participants and their families/caregivers are informed about this process through a written notification.

CYDA is concerned about the unclear terminology used by the NDIA regarding reviews and the NDIS Act should be amended and clarify the review process. For example, there are current challenges with terminology that is not legislated like “light touch reviews” which are used to change the type NDIS plan management and to correct administrative errors. CYDA suggest clearer wording to describe small review changes and describe the specific circumstances to this type of review. Additionally, plan reviews which are regularly due after 12 or 24 months of the current plan can be confused with the “internal NDIS reviews”. Understanding the NDIS language is important to all participants and their families hence an overhaul of current language is needed in the Act and in NDIS processes.

Our organisational members report NDIA reviewers are making phone calls to participants using jargon terms such as “R and N” and unclear language to review decisions. The reviewer must give the opportunity for families of children with disability and participants to have an advocate to help with the review process. A face to face meeting with the necessary supports for all participants should be available.

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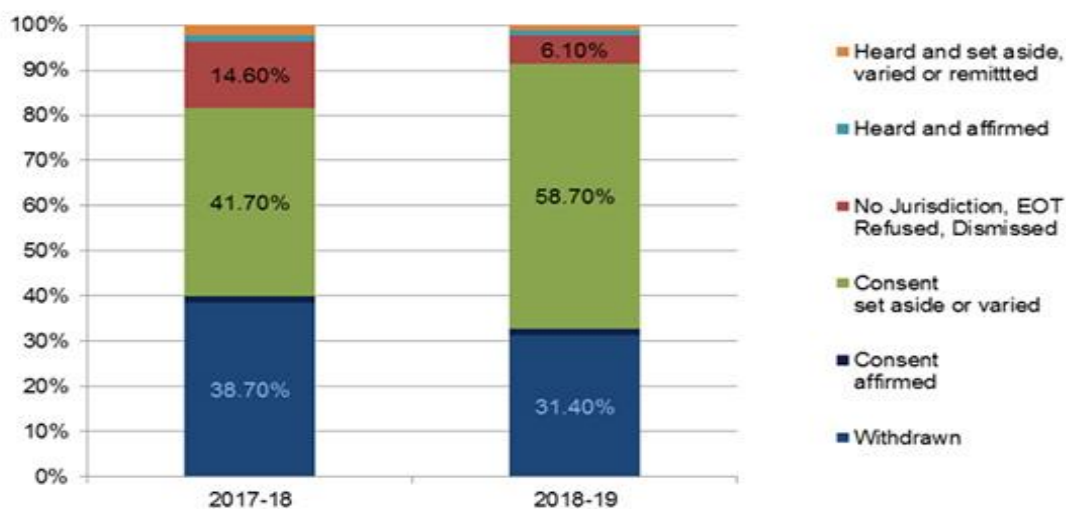
<sup>10</sup> NDIS Act 2013. Section 100. <https://www.legislation.gov.au/Details/C2013A00020>

The Commonwealth Ombudsman received 1,528 complaints about the National Insurance Agency, 256 percent increase from the 429 complaints received the year before<sup>11</sup>. These complaints are the results of the poor communication practices and long waits for decision making by the NDIA and legislative and administrative changes are urgently needed in this area.

When participants are not satisfied with the internal review decision, they can appeal externally to the Administrative Appeals Tribunal AAT however evidence shows that only 802 cases were lodged to the ATT related to the NDIA and from those 441 were finalised<sup>12</sup>, this number is much lower comparing to complaints to the Commonwealth Ombudsman. The appeal process is legalistic and complex, discouraging participants about their right to review, diminishing their choice and control.

The AAT has presented figures for their NDIS cases for 2017/18 and 2018/19<sup>13</sup>:

## Comparison of outcomes



What the above data shows is that only a small percentage of cases appealed to the AAT are actually heard by the Tribunal but the majority of cases are withdrawn or conciliated with the NDIA before hearing with a potential undue influence by the NDIA. The appeal process can be quite intimidating and many participants and their families don't have access to individual advocacy or legal advice to sit in equal terms with the NDIA.

CYDA recommends to review the AAT appeal process and legal supports for participants recording reasons for withdrawing or negotiating with the NDIA as prerequisite before the hearing audience to the AAT.

<sup>11</sup> Commonwealth Ombudsman Annual Report 2017-2018.

[www.ombudsman.gov.au/\\_data/assets/pdf\\_file/0031/89383/Commonwealth\\_Ombudsman\\_AnnualReport\\_2017-18.pdf](http://www.ombudsman.gov.au/_data/assets/pdf_file/0031/89383/Commonwealth_Ombudsman_AnnualReport_2017-18.pdf)

<sup>12</sup> Administrative Appeals Tribunal. 2017-2018 Annual Report. <https://www.aat.gov.au/about-the-aat/corporate-information/annual-reports/2017-18-annual-report/2017-18-annual-report-at-a-glance>

<sup>13</sup> Probono Australia. The Administrative Appeals Tribunal affirms less than 2% of NDIS decisions appealed by participants. <https://probonoaustralia.com.au/news/2019/10/the-administrative-appeals-tribunal-affirms-less-than-2-of-ndis-decisions-appealed-by-participants/>



## Address NDIS interface issues

### Recommendations

Increase transparency about the work of the Disability Reform Council and the NDIA to address NDIS interface issues and monitor progress over time

Consider the legislative changes that may be required to clarify roles and responsibilities between the NDIS and other government funded services

The NDIA and state and territory governments provide accessible information to current and prospective NDIS participants about what the NDIS will fund, and where people can access other services

While the NDIA, the Disability Reform Council (DRC) and the Senior Officials Working Group (SOWG) are working on resolving interface issues across a range of areas and clarifying the principles to determine responsibilities<sup>14</sup>, there is little publicly available information about progress in addressing these issues. There is a lack of clarity on how eligible and non-eligible NDIS participants are provided with services and support, particularly when state and territory governments are withdrawing services. Additionally, service providers of last resort need to be identified so that no child or young person with disability is without support. The review of the legislation provides an opportunity to clarify accountability and responsibilities so participants are not left without a service.

One interface issues for children and young people with disability is in education. Our NDIS national education survey conducted in August and September 2019 with 505 respondents found 57.5% (289) families of students with disability have paid personally (out of pocket costs) for specific supports or equipment to enable access and participation of their child in education. There were 77% (389) students with disability who were NDIS participants and 15.2% (76) of these used NDIS funds to assist in accessing education<sup>15</sup>. Families remain unclear who is responsible for providing these supports, and further consultation and research is needed about the education interface with the NDIS.

The health interface issue for families of children and young people with disability is creating inequity in the scheme as many families on low incomes or have difficulty navigating the health system will have difficulties in obtaining the diagnostic evidence to enter the scheme.

The NDIS Act 2013 Section 34 describes the reasonable and necessary support and paragraph (f) states that the support will be funded by the NDIS if is not appropriately funded or provided through other general systems of service delivery<sup>16</sup>. In reality the experience for families is if their child is not eligible for a support because it is a state or territory government responsibility, it is left to the individual to try and find support without NDIA, ECEI or LAC staff explaining and connecting people to the right government department or agency. The NDIA, ECEI and LAC partners need to play a key role in providing information and connecting people with right services that are not provided

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<sup>14</sup> COAG. Principles to determine the responsibilities of the NDIS and other services systems <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

<sup>15</sup> CYDA (2019) Time for change: The state of play for inclusion of students with disability, Results from the 2019 CYDA National Education Survey <https://www.cyda.org.au/inclusion-in-education>

<sup>16</sup> NDIS Act 2013, section 34. <https://www.legislation.gov.au/Details/C2018C00276>

under the NDIS. There is also need states and territories and the NDIA to collect data on the support services provided to children and young people with disability and to identify service gaps.

## Participant Service Guarantee Service Standards

CYDA believes that the addition of separate principles specifically for children and young people with disability and their families are needed and suggest three additions: *early intervention*, *family centred practice* and *evidence-based practice*.

We also recommend two other principles for all services which are *accountable* and *consistency*. The following table provides an overview of the suggested standards for new principles and additions to the standards provided in the discussion paper.

Principle	Description	Service Standard
Early intervention	The NDIS will provide information, assessment and support at the earliest point when a child experiences disability or developmental delay with the option to waiver evidence requirements	The NDIA ECEI and LAC partners understand disability in children and young people and will inform and assist them in finding support and services or connecting with other government's services to minimise developmental risks.  Support coordination is provided as an option for all plans involving children and young people with disability
Family-centred practice	The NDIA will recognise the important role families play in the lives of children and young people with disability and supporting their learning and development	The NDIA will provide plans that support the child and young person with disability, but also recognise the important role families and carers play  The NDIA will promote the use of family-centred practice in ECI services under the NDIS
Evidence based practice	The NDIA and its partners will include support and services based upon evidence-based practice for children and young people with disability	The NDIA will include services and supports to enable the full participation of children and young people in the community including facilitating access to mainstream services, community environments and activities



Principle	Description	Service Standard
Timely	The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen	<p>The NDIA will support children and young people with disability and their families/ caregivers overcome the barriers to providing evidence for eligibility and will provide interim plans until confirmation of access.</p> <p>The NDIA will allow automatic entrance to the NDIS for participants who were receiving support or services from Commonwealth, states or territories</p> <p>Once the NDIA has appropriate information, access requests are to be made in 20 working days</p> <p>The NDIA will enable advocates, support people and/or other necessary supports for families and prospective NDIS participants during access, pre planning, planning, implementation and the review process.</p> <p>Participants are offered a planning meeting within 10 working days of receiving their 'access met' decision.</p> <p>A draft plan is sent to the participant and their family for review within 20 days so they can request modifications or adjustments</p> <p>Plans are approved within 10 days of the final planning meeting, following the provision of all necessary evidence.</p> <p>Plan amendments are considered within 10 working days of the request.</p> <p>Specialist Disability Accommodation or AT/equipment requests are made within 20 days of the information being provided.</p> <p>Internal review decisions are made within 25 working days of the request after the necessary evidence has been provided. An extension of 20 working days can be made to enable provision of further information</p>

<b>Principle</b>	<b>Description</b>	<b>Service Standard</b>
Engage	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.	<p>The NDIA has ongoing consultation with a wide range of different participants in the scheme, including children and young people and families/carers and advocates</p> <p>The NDIA regularly reports on consultation outcomes in the quarterly NDIA report</p> <p>The NDIA undertakes deep consultation and co-design with Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups, and people with disability living in rural and remote communities to improve NDIS access and operation.</p>
Expert	NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.	<p>NDIA staff and partners will have a high level of training and knowledge about disability, combination of disabilities, participants with complex needs as well as a good understanding of supports needed for participant family/caregivers.</p> <p>The NDIA will train staff in a life course developmental approach across childhood, adolescence and transition to adulthood.</p>
Connected	The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.	The NDIA and state and territory governments work together to improve data and reporting about people with disability who are both eligible and ineligible for the NDIS and their access to universal and state funded services to identify service gaps
Valued	Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance	<p>NDIA to provide assistance through ECEI, LACs to participants and their families during access, planning and implementation process and keep records of further assistance requested and provided.</p> <p>The NDIA will keep records when a person is not eligible for NDIS and referred to other government and community services organisations (linked to service standard connected)</p>

<b>Principle</b>	<b>Description</b>	<b>Service Standard</b>
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.	NDIA will allow participants to review the draft of their plans and will give 20 working days to the participant to provide feedback, or request small modifications.  The NDIA will provide a full explanation of the funds approved in the NDIS plan as well as the rationale when a service or support requested was unfunded and underfunded
Accessible	All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals	The NDIA will provide information in accessible formats and seek feedback from participants and advocates about their understanding of the scheme and support available.  The NDIA will undertake genuine co-design <sup>17</sup> with Aboriginal and Torres Strait Islander people, people from culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and families of children and young people with disability to ensure and inclusive NDIS and ensure barriers to the scheme are addressed
Accountable	NDIA staff and its allied partners are responsible for all the decisions made with a positive or negative impact on participants life and take the appropriate actions to amend decisions when need be.	The NDIA and its partners are accountable to all participants for the decisions they make and there are accessible avenues for making complaints and having them resolved
Consistency	NDIA allied partners provide in all jurisdictions uniform clear and accurate information to all participants and their families/caregivers to avoid misleading information.	The NDIA will develop further staff training on uniform clear and accurate information so the information is the same for all jurisdictions

<sup>17</sup> Co-design is a process used to create products, services and programs. It brings people in as 'design partners', giving a voice to those who are often excluded from the design process. Decision-making, design, information sharing and project planning are among the equal roles between trained designers and design partners, see for example [https://www.futuresocial.org/what\\_is-co-design/](https://www.futuresocial.org/what_is-co-design/)