

National Disability Insurance Scheme

# Consultation Summary: interventions for children on the autism spectrum.

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# 1. CEO introduction

The National Disability Insurance Scheme (NDIS) was born from the idea Australians with disability should have greater choice and control over their own lives with a fair, flexible and consistent package of reasonable and necessary supports.

In the National Disability Insurance Agency's (NDIA) [Participant Service Improvement Plan](#), we committed to more flexible funding of early intervention supports for children and to support and promote children's voice in their own plans, while also working closely with parents and carers.

In May 2020, the NDIA commissioned the Autism Cooperative Research Centre (Autism CRC) to analyse existing research evidence about interventions without medication for children on the autism spectrum who were younger than 13 years.

After this project, the NDIA released a consultation paper to seek input from participants, their families and carers, as well as providers and the disability sector. This was to assist us to consider how we make reasonable and necessary decisions on funding of intervention supports for children on the autism spectrum. The consultation paper sought feedback on the following areas:

- Promoting best practice – information to choose and access best practice interventions.
- Reasonable and necessary – the key principles and delivery standards for autism interventions, explaining our legislative decision-making, holistic approach to (proposed) indicative levels of funded support and gaining insights into situations where extra NDIS supports are needed.
- Support to exercise choice and control – guidance and tools to help parents and carers to implement plans and select providers.
- Conflict of interest - support for families and carers to feel confident to make decisions in the best interest of the child and family.

This paper summarises the activities delivered over a 6 week period and the feedback we received through the consultation on how to improve the NDIS approach for children on the autism spectrum in the future.

We have read your feedback and, where we have received permission, we have published your submissions on our website. Your responses have enabled us to develop our understanding of the various challenges faced by children and families.

We will use this input to continue to improve our guidance and to support families, providers, and our own staff. We will do this through focusing on our early childhood approaches and high intensity supports. We will also continue to work with, and receive advice from the Independent Advisory Council, the Autism Advisory Group, the Participant Reference Group and other representatives as we continue to consider further improvements to our decision making processes.

I want to thank everyone for taking the time to make a submission and provide us with your views. The Agency and I remain committed to working together – with participants, the

disability sector and the broader community – to achieve the goal of making the Scheme better and make sure it's sustainable and available for generations to come.

Regards,

Martin Hoffman

Chief Executive Officer



## 2. What we will do with this feedback

We remain committed to supporting children and families so they can:

- receive timely and appropriate evidence-informed information on early intervention,
- receive funding to support capacity building,
- access supports children need for economic and social participation, and
- make informed decisions and choices on interventions to meet their individual needs.

Based on your feedback, we will not progress with indicative funding bands for capacity building funding children with autism at this time. We recognise the need to continue our work with the sector to understand emerging evidence and best practice interventions. We will continue to develop our understanding of what long term outcomes can be achieved for children through different models of support.

We are also using your feedback to improve our guidance information on:

- how you can use best practice early intervention,
- exercising choice and control, and
- how we make clear and consistent decisions regarding what is 'reasonable and necessary'.

This will enable us to work more collaboratively with parents, caregivers and other professionals to support children to take part in daily activities and achieve the best possible outcomes in their life.

We already have some improvements in progress for release in 2022, they are:

- guides to understanding supports on interventions for children on the autism spectrum which draw on the best available research evidence, and
- a digital resource to support participants and their families to best use their plans.

Other improvements you can expect from us include:

- updating our [Operational Guidelines](#),
- providing examples of 'Would we fund it' for commonly requested items and how we make reasonable and necessary decisions about them, and
- improving the Early Childhood Provider Report form.

We will incorporate what we have learned through this consultation into the Early Childhood Early Intervention (ECEI) Reset project.

We will build on the current report findings by undertaking further work on defining high intensity supports. This will be undertaken through a focus on early childhood intervention high intensity plans and requests. The ongoing work will continue to develop an understanding of the evidence that underpins the use of this type of intervention, the quality and standards required and the outcomes and benefits that may be achieved.

We will continue to listen to people with disability, their families and carers and other stakeholders as we work on these improvements to make the NDIS simpler and fairer.

## 3. How we received your feedback

We received your thoughts, experiences and insights in different ways, including through:

- online submissions,
- consultation events online right across Australia, and
- direct conversations with sector representatives and peak bodies.

### 3.1 Consultation events

During the consultation period, we hosted **12 public information and feedback sessions** for communities across Australia. Our community engagement teams also held local information sessions and met with stakeholders.

We hosted **4 virtual sessions specifically for providers**. We also consulted with participant families through a series of focus groups and engaged with the **Independent Advisory Council** and the **Autism Advisory Group**.

NDIA representatives also held discussions with national peak bodies, academic experts and other stakeholders.

### 3.2 Online submissions

In response to NDIA's request for feedback we received **448 unique online submissions**. Of these:

- 375 responses were from individuals
- 73 responses from organisations

#### Responses from individuals

Who responded	Number	% of individuals*	% of total*
Parent or carer of a child on the autism spectrum	295	78.7%	65.8%
Health or allied health worker	71	18.9%	15.8%
Person on the autism spectrum	63	16.8%	14.1%
Rural/remote	32	8.5%	7.1%
Disability worker	28	7.5%	6.3%

Who responded	Number	% of individuals*	% of total*
Other	23	6.1%	5.1%
Childcare worker or educator	22	5.9%	4.9%
Aboriginal and Torres Strait Islander	7	1.9%	1.6%
Culturally and linguistically diverse	6	1.6%	1.3%

\*Individuals may identify as more than one

#### Individuals who identified as more than one category

Who responded	Number	% of individuals*	% of total*
Parent or carer of a child on the autism spectrum, and a person on the autism spectrum	44	11.7%	9.8%
Parent or carer of a child on the autism spectrum, and a health or allied health worker	28	7.4%	6.3%
Parent or carer of a child on the autism spectrum, and disability worker	17	4.5%	3.8%
Parent or carer of a child on the autism spectrum, and childcare worker or educator	13	3.5%	2.9%

#### Responses from organisations

Who responded	Number	% of organisations*	% of total*
Other	56	76.7%	12.5%
Disability provider	27	37.0%	6.0%
Health or allied health	22	30.1%	4.9%
Advocacy peak (lived experience incl. carers)	7	9.6%	1.6%
Research	6	8.2%	1.3%
Advocacy peak or professional organisation	6	8.2%	1.3%



Who responded	Number	% of organisations*	% of total*
Government department or service	3	4.1%	0.7%

\*Organisations may identify as more than one

### Responses by location

Location of response	Number	Percentage of total***
Victoria	117	26.1%
Queensland	95	21.2%
New South Wales	85	19.0%
South Australia	50	11.2%
Western Australia	39	8.7%
National*	26	5.8%
Australian Capital Territory	15	3.3%
Other jurisdiction**	10	2.2%
Northern Territory	6	1.3%
Tasmania	5	1.1%

\*National – for organisations with operational coverage across multiple states and territories.

\*\*Other jurisdictions – includes the territories of the Indian Ocean and Norfolk Island. This number also includes non-disclosed locations.

\*\*\* the percentage of responses from different states and territory align with participant numbers in those areas, except for New South Wales which was slightly lower.

## 4. What we heard

The feedback we received represented a variety of opinions. We did receive some strong views which were either strongly positive or negative as well as lots in between. Some of the strong themes include the need to:

- Recognise every person on the autism spectrum and their families are different.
- Cater for individualised supports which will generally include learning social, behavioural and / or other coping skills.
- Consider the child and family as a whole across life stages and events.
- Recognise children and families with multiple disabilities live in complex situations which need to be acknowledged and addressed.
- Acknowledge children with a late diagnosis and consider how they will be provided with sufficient early intervention supports.
- Recognise NDIS as one part of a broader system.
- Improve our use of language in any resources which we develop, by:
  - avoiding language that is too clinical and deficit based,
  - strengthening the clinical views where appropriate,
  - demonstrating cultural sensitivity, and
  - writing in plain English, using a narrative style.

In the following pages we have summarised the key themes that we heard, and provided a more detailed breakdown of the submissions that we received in response to the consultation paper '*Interventions for children on the autism spectrum*'. You can also read the full submissions which we have also published [Consultation submissions | NDIS](#) where consent was provided.

### 4.1 Summary

#### 4.1.1 Promoting best practice

This was about getting information to access best practice interventions.

To support participants and families, we heard there needs to be more external information on current best practice, evidence and emerging knowledge. This information should be easy to find and include website links to other key trusted sources. We heard about the importance of information provided by autism organisations and peak bodies. We also heard, families and carers want better information on parental responsibilities and sibling roles.

#### 4.1.2 Reasonable and necessary

This was about standards, principles, decision-making, holistic planning and indicative funding levels.

Our standards and principles were well received. We were reminded on the importance of connecting with other existing service standards and principles.

We were encouraged to keep providing information on our legislative decision-making processes. This includes information to explain how we understand value for money, evidence-based interventions and measuring outcomes.

For holistic planning, the feedback reinforced the need to strengthen connections to health and education supports. We were also reminded, as a part to a larger support-system, we need to encourage where appropriate, strength-based planning for other supports outside the NDIS.

For the indicative funding levels, opinions varied widely with an overall divided sentiment from participants, families and the sector – some felt the funding levels provided helpful clarity, some that they were not sufficiently individualised. At the same time, many people appreciated that this information made available in the discussion paper.

#### 4.1.3 Support to exercise choice and control

This was about helping parents and carers to choose providers and use their plan.

We heard families want us to develop questions matched with suggested responses. This is because while talking with providers, this is useful for what a family should expect to hear to indicate best and evidence informed practice.

This consultation theme received the most support.

#### 4.1.4 Conflict of interest

This was about parents and carers feeling confident to make decisions in the best interest of their child and family.

We heard parents and carers think it is fair for them to request a provider to declare any real or perceived conflict of interest. The feedback also reinforced it is best practice for providers to match supports to participant goals and to explain the expected outcomes from these supports. We heard from participants and families it is reasonable for the Agency to ask for reports from providers. This is because provider reports on progress and outcomes help inform us around future funding decisions.

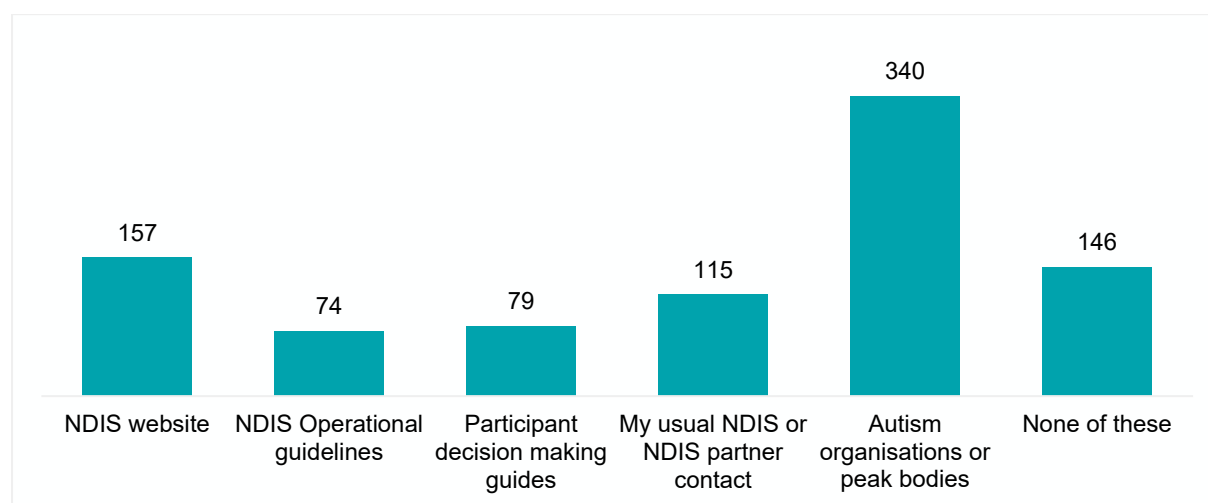
## 5. Appendix

### 5.1 Promoting best practice

#### 5.1.1 Question 1

**We asked:** Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?

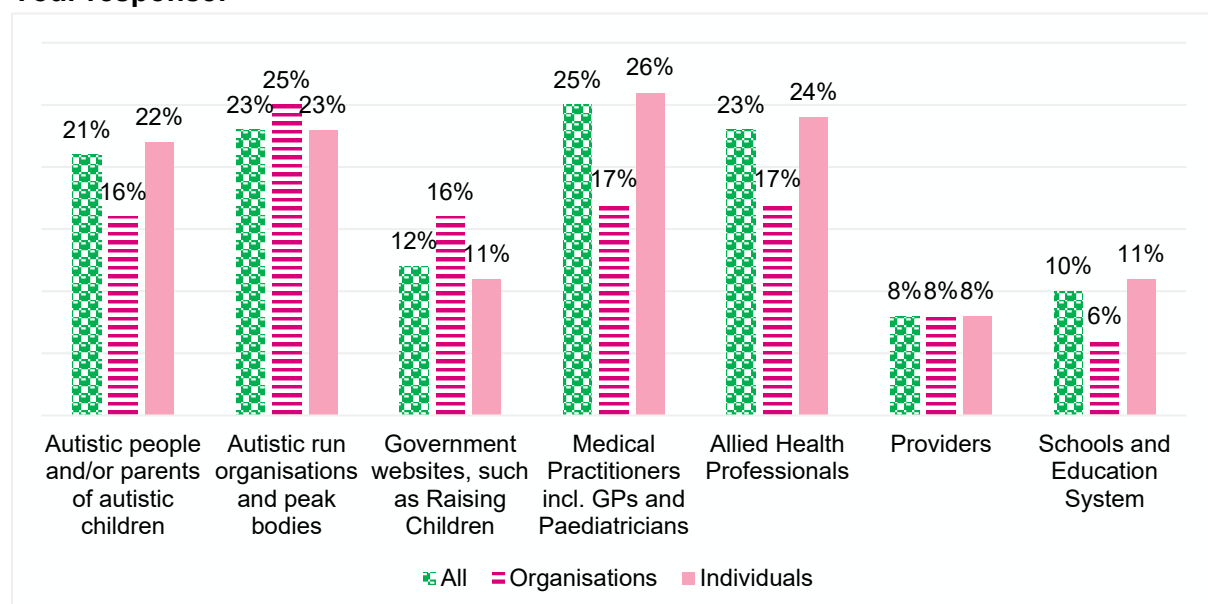
**Your response:**



#### 5.1.2 Question 2

**We asked:** Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

**Your response:**



Some of the key themes included:

- Families expressed they often struggle after receiving an autism diagnosis and would like to connect with other families that have children with autism.
- Families want accurate and impartial information as early as possible
- Families want to understand professional roles and more about available interventions.
- The following websites/documents were mentioned by families as good sources of information:
  - [Raising Children](#)
  - [Autism CRC early intervention report](#)
  - [NDIS Operational Guidelines](#)
  - [The Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice' 2012.](#)

#### Examples from submissions:

*'It would have been very helpful if NDIA resources provided access to comprehensive information relating to all possible therapies and their related evidence.'* ([Parent of a child on the autism spectrum](#))

*'Providers are most likely to access information about best practice interventions from the available published literature, professional peak bodies, industry relevant sources and the NDIS website.'* ([Provider of early intervention](#))

*'Families are more likely to access information from the NDIS website, their NDIS early childhood partner, trusted local providers and through peer contacts and disability groups/organisations.'* ([Provider of early intervention](#))

*'As a parent of autistic children I seek out the lived experiences of autistic adults. Autistic-led organisations and advocacy groups are my go-to for additional information.'* ([Parent of a child on the autism spectrum](#))

#### 5.1.3 Question 3

**We asked:** Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. How can we help families to find and connect with other supports outside of NDIS?

**Your response:** the overall sentiment was neutral. Organisations were more positive about the value of holistic planning than individuals.

Some of the key themes included:

- There is need for easier connections with mainstream supports. This includes accessing inclusive services, reducing wait times, better understanding of reasonable adjustment obligations and how other services interface with the NDIS.
- Being able to connect and receive information from planners, support coordinators, and local area coordinators is important.

- Families want to be able to connect with support groups and peer support in local and online communities.
- Families want better access to information, resources and training in their local area.
- Families want better understanding of parental responsibility and how the capacity of the whole family, including siblings, can be built.

#### Examples from submissions:

*'Perhaps education of the carer should take a greater role. Webinars, mixed media learning resources, reading lists, literature reviews, community and academic courses for parents/carers can be fantastic for referral / identifying support. There can also be a mine field of information with limited relevance'. (Parent or carer of a child on the autism spectrum)*

*'It would be helpful for NDIA to work more holistically with other services available in the community and through other Government services to trouble shoot the interface issues that arise. Of course, this requires significant resourcing both on the NDIA end as well as the other service systems to understand, explore and find solutions for some of the systemic issues people with disability experience when trying to access the services they should be entitled to across all levels of the Australian community.' (Unidentified)*

*'Provide support coordination in all client plans ages 0-7.' (Health or Allied Health professional)*

## 5.2 Reasonable and necessary

### 5.2.1 Question 4

**We asked:** Building from the [Autism CRC research](#) the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum. Is there anything you would like to add?

**Your response:** the overall sentiment from individuals and organisations was neutral. The stronger negative sentiment from individuals related to a sense that the principles did not capture or could not be easily related to the core characteristics of autism.

Some of the key themes included:

- We need to use more strength based language during conversations with participants and in all official communications,
- It was not clear the principles related specifically to children on the autism spectrum
- Principles were not written in plain English
- There was concern about how the principles would work in practice, and who would be accountable for monitoring their effectiveness,
- Strong sentiment was expressed, both towards and against, behavioural interventions, and
- Respondents want to see family supports incorporated into the principles.



### Examples from submissions:

*'Where possible, the intervention actively involves the person's parent/carer.'* ([Parent or carer of a child on the autism spectrum](#))

*'I think you need to be careful with this approach as your interpretation of appropriate early intervention may differ to others and it is hard to define. I would like to see some statement around consultation with professionals and families and what is best for the participant.'* ([Parent or carer of a child on the autism spectrum](#))

*'Like the Autism Spectrum interventions can't be bundled into to true and tested means. What might work for one participant may not work for another and putting a condition on the interventions must be logical and scientifically plausible and has research evidence, or may not provide the best outcome for participants.'* ([Parent or carer of a child on the autism spectrum](#))

### 5.2.2 Question 5

**We asked:** Building from the [Autism CRC research](#), the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum. Is there anything you would like to add?

**Your response:** the overall sentiment from individuals and organisations was neutral. Similar to the sentiment for the principles, individuals expressed more negative feedback than organisations. This sentiment related to a sense that the standards did not reflect how they related to the core characteristics of Autism

The key themes were similar to those listed in question 4.

### Examples from submissions:

*'These standards are OK, provided that decisions about best practice interventions based on these standards are based on research evidence and the individual needs of the child'.* ([Parent or carer of a child on the autism spectrum](#))

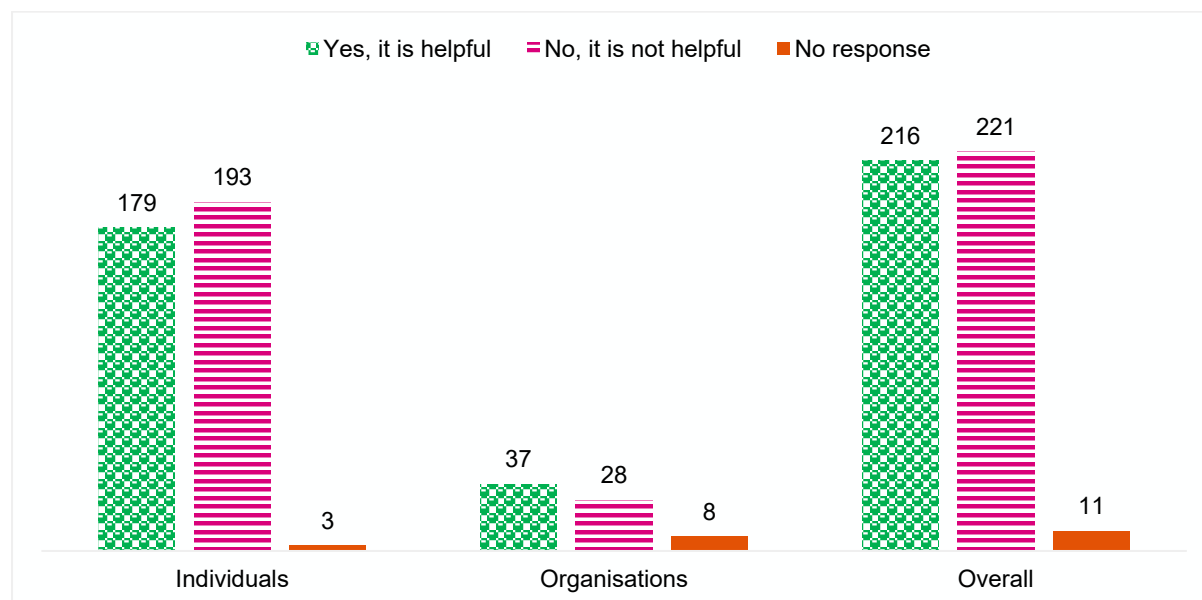
*'The intervention needs to be culturally appropriate for traditional Aboriginal people from remote communities, and to be delivered in a culturally appropriate manner. This includes developing a trusting relationship between therapist and the family involved and may require some flexibility to adapt to the remote community environment.'* ([Organisation working with Aboriginal and Torres Strait Islander women](#))

*'Consideration that benefits can sometimes look like maintaining function, rather than improving function, so that further deficits do not occur.'* ([Parent or carer of a child on the autism spectrum](#))

### 5.2.3 Question 6

**We asked:** ‘Reasonable and necessary’ is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by ‘reasonable and necessary’?

**Your response:**



### 5.2.4 Question 7

**We asked:** Do you have any other feedback about how we explain ‘reasonable and necessary’?

**Your response:** The sentiment was divided. Some submissions expressed they appreciated the information on decision making, even if they did not agree with the outcomes.

Some of the key themes included:

- There was strong feedback that the case study examples were too narrow and not based in real life. De-identified real examples would have been preferred.
- There were suggested improvements relating to being able to apply different circumstances for the child and family in an interactive case study that would help the reader to understand reasonable and necessary decisions and funding outcomes.
- There were mixed views on reasonable and necessary:
  - Language used (too complex, not real life),
  - Funding (too low, good to see transparency, expectation on parents),
  - Equity (gaps in community and mainstream services, not real life enough, social economic overlay), and
  - Still unclear what value for money means and where parental responsibility starts and ends

- While submissions appreciated the transparency of the NDIA in providing this information there was a need to put greater thought into ensuring in future that case studies or scenarios are clearer and more realistic.
- Reasonable and necessary information needs to focus on being clear and concise to demonstrate transparent decision making.

### Examples from submissions:

*‘Provide more realistic examples to accurately reflect the support needs of most children with autism and the evidenced based interventions that have shown to reduce support needs in the future.’* ([Parent or carer of a child on the autism spectrum](#))

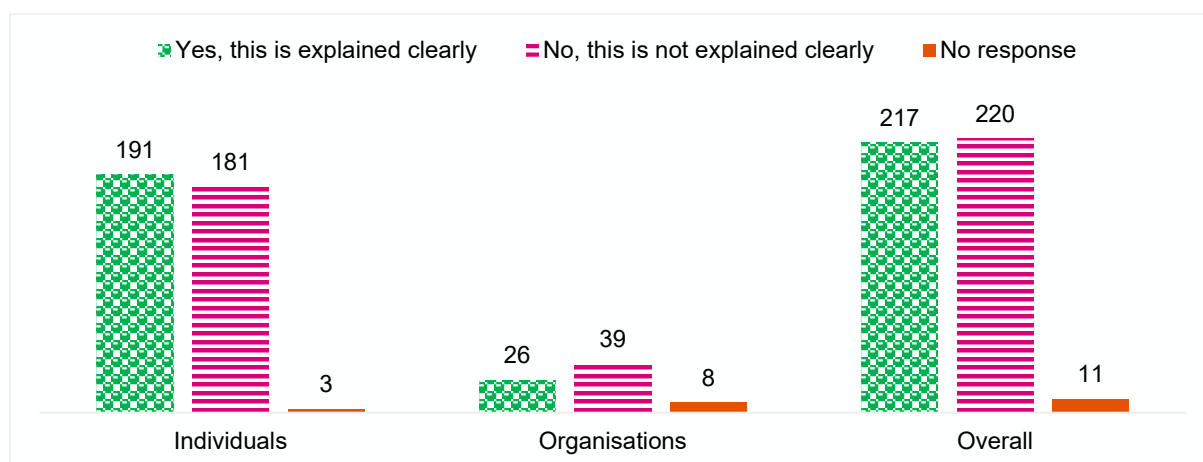
*‘Case studies and the considerations presented should be accessible through various mediums such as animated explainer videos. Additional guidance on interventions supported by the NDIS and considered reasonable and necessary may be beneficial to families. This would be of particular benefit where planners do not have an allied health background and may not have the experience to interpret clinical information and evaluate the evidence base for an intervention.’* ([State Government Education Department](#))

*‘Much clearer advice needs to be published. It should be precedent based to ensure it is applied consistently. It must centre the voices of Autistic people and carers. The NDIS needs to apply it consistently and transparently. LACs need to be adequately trained. Reasonable and necessary needs to be applied fairly and transparently and with the best interests of the PWD at heart. They must not be applied simply to reduce costs to the NDIS.’* ([Parent or carer of a child and person on the autism spectrum](#))

### 5.2.5 Question 8

**We asked:** Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain indicative levels of funded support for children on the autism spectrum (Section 7.5.) Do these table/s clearly explain the indicative levels of funded supports?

### Your response:



### 5.2.6 Question 9

**We asked:** Do you have any other feedback about how we explain the indicative levels of funded supports?

**Your response:** The indicative tables of supports generated the most feedback from the consultation paper. The commentary was more negative than positive.

Some of the key themes included a range of views and questions about:

- The descriptors and amounts of funding in the levels.
- How the levels were determined (methodology), how and whether a participant could move between levels?
- If and how multiple disabilities were considered?
- If and how family capacity building would be considered?
- If and how transitions and maintenance of skill were factored in?
- Whether the levels were linked to, or based on, Autism diagnostic levels?
- The language used to describe areas of need, characteristics and levels. Some wanted this to be more clinical language while others preferred a plain English approach.
- Whether funding should be based on the age of the child, or the number of plans that they have had?

#### Examples from submissions:

*‘Great this gives me an indication of the funding I will have. Now, I can find the therapy and providers to work with.’* ([Parent of a child on the autism spectrum](#))

*‘Autism is a spectrum that does not fit neatly into tick boxes or a table.’* ([Parent of a child on the autism spectrum](#))

*‘It would be helpful to have a definition of High, Medium and Low needs and to also define the areas you will be considering, some examples are given but there is no clear list of areas.’* ([Parent of a child on the autism spectrum](#))

*‘The levels could be improved by acknowledging the family’s capacity and setting. Given the focus on family involvement in interventions, the family’s capacity to do this should be recognised and considered in the funding levels.’* ([Provider of early intervention](#))

*‘The indicative levels of funded supports should not be aged based but be based on how many years the child (or adult) has had NDIS funding for therapy. Instead of under age 7, it should be - in the first - 2nd year. 3rd - 4th year. 5th year and more.’* ([Parent of a child on the autism spectrum](#))

### 5.2.7 Question 10

**We asked:** There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

**Your response:**

Some of the things that you said we should consider included:

- the age of the child and how recent the diagnosis was received,
- whether the child has a secondary diagnosis to autism,
- whether the family lives in rural or regional areas,
- individual family circumstances,
- cultural considerations,
- the role siblings have in a family,
- maintenance of capacity that has been built, and
- major life transitions such as starting high school, puberty, moving houses, changes in family circumstances.

**Examples from submissions:**

*'There needs to be flexibility and or contingency funding for transitional periods e.g. starting school, puberty, high school etc. Or when a child goes through a period where their functioning reduces for whatever reason it might be.'* (Parent or carer of a child and person on the autism spectrum)

*'You need to consider the family dynamic - is this a single parent household? Are there other high needs children in the family? Are the children living between two homes? Funding equipment and consumables for only one home is ignorant to how most families live these days. NDIS funding is confusing, hard to access, scary to use, inconsiderate of the individuals truly unique needs and misses how most families live.'* (Parent or carer of a child on the autism spectrum)

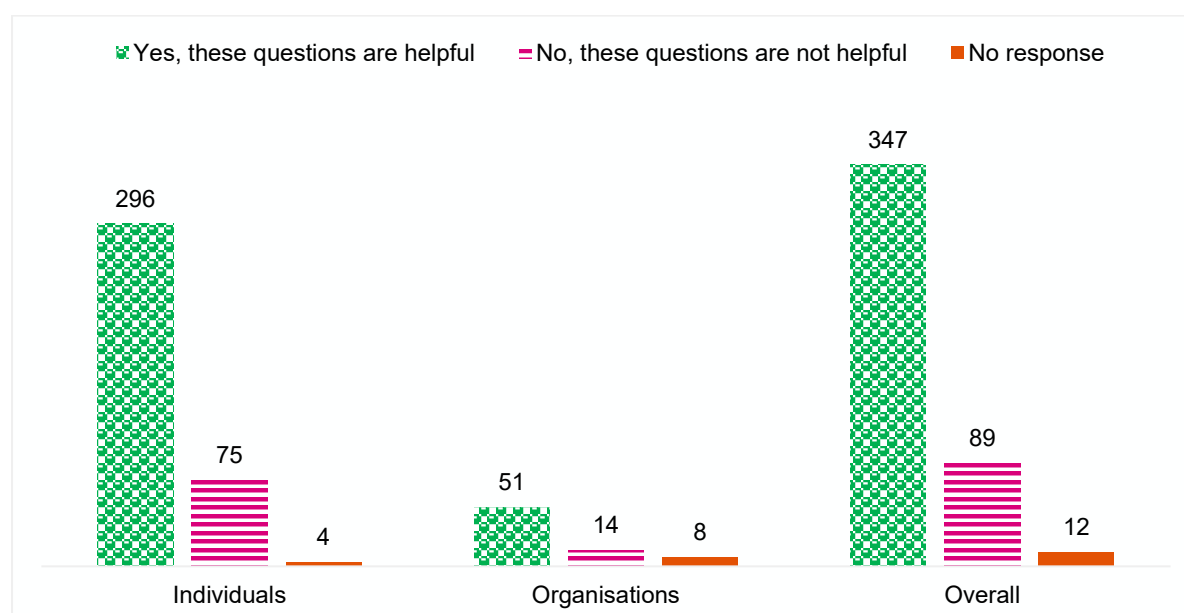
*'The impact on the family of the child's disability; the parents and carers mental health and well-being as well as siblings, and if the parents or carers have more than one child with a disability. Geographical or demographics of the area the child and family are located; rural or isolated areas may find it difficult to access services. What support or extra support can be offered to those participants?'* (Parent or carer of a child on the autism spectrum)

## 5.3 Supporting parents and carers to exercise choice and control

### 5.3.1 Question 11

**We asked:** We want to support children and parents with implementing plans using the Autism CRC research and best practice. In Section 8.2 there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

**Your response:** this question had the highest amount of positive sentiment out of the consultation questions across both individuals and organisations. We interpreted this as an indicator of overwhelming support to develop the questions listed in the consultation paper into an externally available resource.



### 5.3.2 Question 12

**We asked:** What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

**Your response:**

- There is further consideration required for ensuring guidance or tools are culturally appropriate. For example, in some communities asking direct questions may not be culturally appropriate.
- There were concerns raised that in areas there is limited choice and thin markets that families may have to work with service providers regardless of the answers.
- Some people were concerned that they would be declined a service or not added to a waiting list, if they asked questions.



- There was concern that not all professionals understand Autism and that this may impact on the child's progress and families confidence.

#### Examples from submissions:

*'We need lists of providers, the services they offer, the fact that their services are evidence based and proven to deliver results, maybe some form of accreditation. We need both low and high intensity interventions to be covered and it would be ideal if we had family feedback on service providers - indicating the progress made and the types of tools used to judge progress.'* (Parent or carer of a child on the autism spectrum)

*'Implementation of a service agreement document that is standard in terms of expectation of service provision (e.g. How many sessions, cost, frequency of progress reviews), and is also a collaborative document about agreed best approach for the individual child, team approach (parent, child, therapist team), and expressed wishes for how the support is provided, including training etc.'* (Parent or carer of a child on the autism spectrum)

## 5.4 Conflicts of interest

### 5.4.1 Question 13

**We asked:** This question relates to [Section 8.3](#) of this paper: "Addressing conflicts of interest." How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

**Your response:** Most responses from individuals and organisations was neutral.

Some of the key themes included:

- The NDIA should:
  - encourage flexibility between providers and families for contracts and agreements,
  - require providers to declare any real or perceived conflicts of interest in any reports or submissions, and
  - empower families with access to unbiased information on early intervention supports and therapies, with links to local support groups and autism organisations
- There was concern that the NDIA had not considered professional ethics and codes of conduct of allied health professionals.

#### Examples from submissions:

*'Provide further support particularly for first plan to develop options and discuss what each provider is meant to do.'* (Parent or carer of a child on the autism spectrum)

*'This is a really tricky one. I'm going to sound like a broken record but I again think the best help would be to direct parents to a space where they will hear autistic voices. We don't*

*know what each child needs but our voices need to be heard alongside specialists.'* ([Person on the autism spectrum](#))

*'Providers, participants, and families need clearer, more transparent information on supports and processes. It might help both providers and families to average and make available estimated time ranges and price ranges for different categories/types of support so that people have some idea of what to expect and what kinds of results might be anticipated. Helping families and providers understand the overarching, long-term importance of working towards participants being able to enter mainstream or community supports and involvement when possible could also help align goals and priorities and allow suggestions for care to remain more focused on the child's best interests.'* ([Disability service provider](#))