

National Disability Insurance Scheme

Consultation paper: Interventions for children on the autism spectrum

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1. What this paper is about and how you can help

The National Disability Insurance Agency (NDIA) recognises the importance of working with participants, providers and the disability sector when making improvements to our policies and procedures. This reflects our continued commitment to open engagement to collaboratively improve participant experience and outcomes.

This paper seeks input and feedback from participants, their families and caregivers, as well as providers and the disability sector to assist in developing clearer advice on National Disability Insurance Scheme (NDIS) funding of early intervention services for children on the autism spectrum.

For the purpose of this discussion paper and in line with the scope of the Autism Cooperative Research Centre (Autism CRC) research paper, we define children as those aged under 13 years.

We acknowledge that when referring to individuals on the autism spectrum there is no one term that is preferred by all people. For the purpose of this report we are using the terms children on the autism spectrum or person on the autism spectrum.

We know that there are different views on what effective early intervention for children on the autism spectrum means and are keen to hear your feedback. We will work with participants, families, caregivers, providers and the sector to shape the path forward. You are invited to comment on some or all of the aspects of this paper.

We welcome feedback from participants, people on the autism spectrum, their families and care givers, providers, academics, professionals, representative organisations, and the broader community.

Feedback can be submitted via the [NDIS website](#) up until 10 am AEST Monday the 30 April 2021.

We will also run workshops with participants, representatives from the autism, government and non-government sectors to gather feedback.

2. Introduction

The NDIA is developing advice for participants, their families, and providers regarding reasonable and necessary funding of early childhood intervention supports for children on the autism spectrum.

This work forms part of the Australian Government response to recommendations of the 2019 [Review of the National Disability Insurance Scheme Act 2013](#) (NDIS Act) completed by Mr. David Tune AO PSM (Tune Review), and reflects advice from the NDIS Independent Advisory Council (Council) on [Promoting best practice in Early Childhood Intervention in the NDIS](#).

As a first step in the development of this advice, the NDIA commissioned the Autism CRC to analyse existing research evidence for non-pharmacological interventions (interventions without medication) for children on the autism spectrum aged under 13 years.

The report from this work 'Interventions for children on the autism spectrum: A synthesis of research evidence' was released in November 2020 and is available on the NDIS [website](#). It provides an independent and comprehensive, picture of the current evidence base compiled by some of Australia's leading autism experts from research and clinical fields, including people on the autism spectrum. It updates previous work undertaken or commissioned by the NDIA to support best practice in this area on behalf of participants and their families.¹

The research evidence will help to inform an NDIS policy position on the funding of reasonable and necessary early childhood intervention supports for eligible NDIS participants and their families, aged under 13 years. It is important for the NDIS insurance approach that the Scheme funds evidence-based interventions, in the right circumstances underpinned by best practice to enable the greatest long-term outcomes for children on the autism spectrum.

This consultation process will help us understand your views with so that we can:

- a. update existing policy and operational guidance to support the delivery of clear and consistent reasonable and necessary decision making under the existing legislative framework for early intervention for children

¹ Previous research or best practice developed commissioned by the NDIA has included: [Autism Spectrum Disorder: Evidence-based/ evidence-informed good practice for supports provided to preschool children, their families and carers. \(2016\)](#); [ECIA - National Guidelines: Best Practice in Early Intervention](#); [National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia](#)

- b. refine policy and operational guidelines to support the implementation of evidence-based, best practice early intervention for children on the autism spectrum in the new context of personalised budgets and plan flexibility from late-2021
- c. improve guidance for parents and carers to exercise choice and control over the early intervention supports to enable their children to take part in daily activities and achieve the best possible outcomes throughout their life
- d. work more effectively with parents, caregivers and other professionals to collectively deliver the best outcomes for children on the autism spectrum and their families.

3. Current context

As at 30 December 2020, there were around 137,000 participants on the autism spectrum, including around 80,000 children aged under 13 years.

The convention of the United Nation's Convention of the Rights of the Child recognises that a child has the right to special care, education and training. This helps the child build their skills to take part in everyday activities and enjoy a full and decent life. The NDIS is designed to support to this.

In line with NDIS insurance principles, we take a lifetime approach, investing in people with a disability early to improve their outcomes later in life. We focus on lifetime value for Scheme participants by funding competitively priced, best-practice supports that deliver benefits and outcomes for participants.

In addition to providing individual supports to eligible participants, the NDIS provides people with disability with information, referrals and connections to mainstream services in their communities. For children, this may include health services, early childhood development and care services, play groups, recreational activities, libraries and early education through schools, as well as information about what support is provided by each state and territory government.

Under the NDIS Act, the NDIA is required to make decisions about the individual supports included in a participant's plan in line with reasonable and necessary criteria. The NDIA is currently consulting on a range of reforms that are designed to improve the overall operation of the Scheme and provide participants with greater choice and control over their supports. You can read more about these reforms on the [NDIS website](#).

We are looking to reset the current [NDIS Early Childhood Early Intervention approach](#) to improve the different ways we support young children and their families to reach their full potential.

Separate to this report, we have consulted on a new [Access and Eligibility Policy](#) involving the introduction of independent assessments from mid-2021 to improve the speed consistency and equity of NDIS access decision making.

We have also consulted on a new [Planning Policy for Personalised Budgets and Plan Flexibility](#) for commencement in late 2021. Under this proposed policy, a participant's plan will be informed by the results of an independent assessment so that plan budgets more closely reflect participant's functional capacity, individual circumstances and environmental context.

Personalised budgets will provide much greater flexibility in how a participant uses their NDIS funding. You can read more about the new Access and Planning Policies on the [NDIS website](#).

4. Opportunities for improvement

The NDIS was established to support the independence and social and economic participation of people with disability by providing reasonable and necessary supports to participants.

The Tune Review found that participant's experience of interacting with the NDIS could be improved. Some participants reported that they find the NDIS confusing and difficult to navigate and are frustrated by delays and a lack of transparency and consistency in how the NDIA makes decisions.

We received similar feedback when we engaged families, carers and the early childhood sector about resetting the NDIA's early childhood early interventions approach.

People are wanting clarity about how we make decisions on what is considered reasonable and necessary early intervention supports for children on the autism spectrum.

In seeking to provide this clarity, we are aware of a number of issues and challenges:

- a. while there is general agreement that the NDIA's early childhood early interventions approach reflects best practice principles, implementation of the approach remains variable from one place to the next
- b. there are differing views on what constitutes effective early intervention for children on the autism spectrum, and varying quality of practice in early intervention for children, their families and carers
- c. inconsistency in the NDIA's decision making is leading to unnecessary requests for plan reviews and appeals to the Administrative Appeals Tribunal which are stressful and anxiety provoking for children and families
- d. the advice and supports available to families and carers to help them find the right services for their child are patchy and inconsistent
- e. once an NDIS plan is agreed, there is not always enough information and assistance to help families and carers exercise informed choice and control to implement their plan effectively

- f. children, families and carers are at times given conflicting information and advice by multiple agencies involved in the planning and provision of supports for their child
- g. many families, particularly where diagnosis is recent or during the first NDIS planning cycle, may feel overwhelmed and unable to take on board all the information shared with them
- h. there are potential conflicts of interest in a participant's chosen early childhood provider or practitioner being a supplier of information to inform the planning and budget allocation process, as well as the provider of supports.

5. Summary of research findings

The NDIA engaged the Autism CRC to provide:

- a narrative review of non-pharmacological interventions (interventions without medication) that have been developed for children aged under 13 years on the autism spectrum, and the Australian training pathways for clinical practitioners who provide these
- an umbrella review of the evidence available on the therapeutic (and other) effects of these interventions.

The report 'Interventions for children on the autism spectrum: A synthesis of research evidence' was released on 9 November, 2020. Links to the full report and fact-sheets can also be found on the [NDIS Website](#).

The NDIA acknowledges that research and evidence on autism interventions is a growing field. In this context, the Autism CRC's research provides a comprehensive snapshot of the current range of research evidence.

Narrative Review

The Autism CRC narrative review includes a broad overview of interventions for children on the autism spectrum, including the principles underpinning all interventions, and the rationale behind each category of intervention, such as developmental interventions, behavioural interventions or technology-based interventions.

With regards to **early intervention best practice** (including its application) the research identifies the following core principles to be considered for children on the autism spectrum.

Table 1: Core principles that are important to interventions for children on the autism spectrum

Core principle	Description
Holistic assessment	An initial assessment of an individual's strengths, challenges, goals, and preferences is critical to developing intervention targets that are meaningful to the child and family.
Individual and family-centred	The person on the autism spectrum, and their family members, are the individuals receiving clinical services, and are to be considered equal partners with clinical practitioners.
Lifespan perspective	The types of interventions and supports that are most appropriate will change across the life-course, as children move from early childhood settings into school, and ultimately adult life.
Evidence-based	Intervention is most effective and safe when it is based on the best available research evidence, combined with evidence from clinical practice and the preferences and priorities of fully informed children (to the extent possible) and families.

The review also identified three **key professional training pathways** typically required to deliver interventions for children on the autism spectrum in Australia.

1. **Pathway one** – interventions can only be used by professionals with discipline-specific competencies
2. **Pathway two** – interventions can be used within scope of practice, and may include interventions relevant to children with a range of neurodevelopmental conditions
3. **Pathway three** – interventions can be used if within scope of practice and following additional training.

Umbrella review of evidence

The authors of the umbrella review systematically searched for and extracted data from all relevant previously published systematic reviews. The review paper presents summaries of the latest research evidence on interventions for children on the autism spectrum. This included 58 interviews and 1787 unique studies. The authors looked for evidence of impact on the following important outcomes:

- **Core autism characteristics:** overall autism characteristics, social communication, restricted and repetitive interests and behaviours, and sensory behaviours
- **Related skills and development:** communication, expressive language, receptive language, cognition, motor, social-emotional and challenging behaviour, play, adaptive behaviour and general outcomes

- **Education and participation:** school/learning readiness, academic skills, quality of life, and community participation
- **Family wellbeing:** caregiver communication and interaction strategies, caregiver social emotional wellbeing, caregiver satisfaction, caregiver financial wellbeing, and child satisfaction.

The umbrella review found there is no 'one size fits all' approach to intervention during childhood, and there is no one intervention that improves all developmental outcomes for all children. It recommended that interventions should be selected on an individual basis within an evidence-based practice framework. The report outlines that an evidence-based practice framework should combine the best available research evidence, with evidence from clinical practice, as well as child and family preferences and priorities.

Specifically, the report found that:

- there was no consistent evidence as to whether the amount of intervention influenced child and family outcomes
- there was variable evidence with regards to the impacts and outcomes related to the range of reviewed interventions
- there was not enough evidence to determine whether particular delivery characteristics (e.g. individual or group delivery; clinic, home or school setting, face to face or tele practice) may maximise the effects of an intervention and, if so, for which children
- importantly, with regards to child and family preferences the research found that caregiver involvement in an intervention had a similar, and at times greater, effect on child outcomes compared to interventions delivered by clinical practitioners alone
- there was evidence that either parent or caregiver-mediated and peer-mediated interventions had a positive effect on a range of child and family outcomes
- there were some positive effects identified for different categories of interventions however the impact on child and family outcomes was variable. This included interventions such as behavioural interventions, developmental interventions, Naturalistic Development Behavioural Interventions (NDBIs), technology-based interventions, and Cognitive Behavioural Therapy (CBT) however the impact on child and family outcomes was variable
- positive intervention effects for sensory-based interventions were reported for certain intervention practices only, and in those cases, positive effects were limited to select child and family outcomes
- a mix of inconsistent and no effects on child and family outcomes were reported for both TEACCH® and animal assisted interventions

- among 'other' intervention practices, only social skills training had evidence for a positive effect on child outcomes
- children on the autism spectrum and their families may benefit from the expertise of a range of clinical practitioners including health, education and medical disciplines
- training to deliver intervention practices typically involves the completion of a professional qualification (e.g. a relevant university degree) and professional registration
- some intervention practices can be delivered by a range of professional disciplines, while others can only be delivered by certain professional disciplines. Some intervention practices require additional training before they can be delivered.

6. Potential implications on NDIS decision making

There are many interventions available for children on the autism spectrum with no 'one size fits all'. Learning about these interventions can sometimes be challenging for families, clinical practitioners and educators. One thing that is clear, is the role of parents and caregivers is as important as professionals when supporting their child's development.

The Autism CRC's research along with other evidence and research are being used to inform future NDIS operational guidelines, and increased transparency on reasonable and necessary supports. Some of the other considerations include:

- key principles for autism interventions
- standards for the delivery of autism interventions.

6.1 Key principles for autism interventions

The research and early childhood best practice supports seven key principles to inform NDIS reasonable and necessary decisions related to early interventions for children on the autism spectrum.

1. The intervention is based on a good understanding of autism

As identified through the Autism CRC Research much has evolved in our understanding of autism. We learned that some interventions are based on flawed theories of autism and the causes of autism. For example, some of the first interventions to be used were based on the incorrect belief that autism is caused by so-called 'refrigerator mothers': mothers whose denial of emotional warmth causes their babies to turn away from other human beings and become autistic. We now know that this theory is false. Most researchers believe that autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors that affect a number of different areas of the brain.

Other interventions are designed to ‘cure’ autism, despite the fact that autism is not an illness or a disease. These interventions do not usually consider how different each person is from others on the spectrum, and none have been shown to work. Furthermore, the idea of curing autism goes against the views of some in the autism community who do not want to be cured and would rather that research and support funding be spent on assisting the person to be supported with everyday practical problems such as traveling safely, assistance in social interactions and making friends, or finding a job.

2. The people who deliver the intervention know the person well and respect their feelings and views

People who deliver an intervention should know the person they are working with well – because every person on the autism spectrum is different. People who deliver an intervention should also respect the person’s feelings and views. Many principles of better practice recommend that all health and social care professionals providing care and support for people with autism should:

- aim to foster the person’s autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, people with autism are available in appropriate language or formats, including various visual, verbal and aural, easy-read, and different colour and fonts
- consider whether the child/family may benefit from access to a trained advocate.

Many people delivering interventions require the requisite training and qualifications and should work very closely with the child / families as equal partners.

3. The intervention is based on theoretical principles that are logical and scientifically plausible

A number of interventions for people on the autism spectrum are based on illogical and implausible theories. Sometimes these are flawed theories about the nature of autism and sometimes these are flawed theories about how the intervention itself is supposed to work.

One intervention that is scientifically implausible is homeopathy. According to [Better Health Channel](#) there have been several reviews of the scientific evidence on the effectiveness of homeopathy with no evidence that homeopathy is effective as a treatment for any health condition. In Australia, in 2015, the National Health and Medical Research Council (NHMRC) released a Statement on Homeopathy based on its own review of available clinical evidence. NHMRC also concluded there is no reliable evidence that homeopathy is effective for any health condition: ‘The ideas that underpin homeopathy are not accepted by mainstream science, and are not consistent with long-accepted principles on the way that the physical world works.’

4. The intervention is adapted to the needs of the person receiving it

Interventions should be adapted to meet the needs of the individual on the autism spectrum because each person on the spectrum is different. For example, some people on the autism spectrum have over-sensitive senses. They may find certain sounds physically painful or they may not be able to wear certain clothing because they find the fabric uncomfortable. Some people on the autism spectrum have under-sensitivity. They may seek out strong flavours, as they are unable to taste bland food, or they may rock or spin to stimulate their senses of movement and balance. So, an intervention designed to help someone on the autism spectrum deal with their sensory sensitivities would need to take into account the specific sensitivities of each individual.

Also, some interventions not originally designed for people on the autism spectrum can still be beneficial to them if they have been adapted to their needs. For example, visual supports, visual strategies and visual cues are general terms for tools that present information using symbols, photographs, written words and objects across many disabilities. One of the most common visual supports is a visual schedule, sometimes called a picture schedule. This is a set of pictures that show activities or steps in specific activities. For example, a visual schedule can show all the activities in a single day, or all the steps involved in a specific activity like eating a meal.

There is no 'one size fits all' approach to intervention during childhood, and there is no one intervention that improves all developmental outcomes for all children.

5. Research evidence shows the intervention can work for people on the autism spectrum

Evidence-based interventions are important as the evidence provides assurances that they have been tested similar to health and medical practice, and that they have been assessed for risks. While evidence in favour of an intervention does not guarantee that it works with every person with autism, it does provide some reassurance to people who are thinking about using it.

Many interventions used with people on the autism spectrum (including many forms of adaptive and assistive technology such as computer apps, smart phones and visual schedules) have limited or no research evidence. This does not mean that they do not work; it may simply mean that more research is required to find out if they do work.

Also, some interventions (often not evidence-based) appear to be marketed to play on a person's guilt or anxieties to convince them to pay to use the intervention. These interventions may not be designed with the person specifically in mind, may not work and often risk people's time and money. The [Raising Children's Network](#) provides updated and regular information for parents and carers.

Evidence-based interventions are important as the evidence provides assurances that they have been tested, and that they have been assessed for risks.

Interventions should be individualised to meet the child and family needs and be evidence-based, at the right time / frequency and be clear at the beginning on expected outcomes.

6. The intervention works in the real world, not just in a research laboratory

Interventions should work in the real world. Many autism interventions start off being tested in research settings – where as many variables as possible are controlled. However, in the real world, it is often not possible to control for things like the level of training and experience of the person giving the intervention, the room where the intervention takes place, how often it can take place, and who takes part in the intervention. Because of this, a number of interventions have been shown to be less effective in the real world compared to research settings. For example, some forms of theory of mind training have been shown to be effective in laboratory settings, but seem to be ineffective in real-life situations.

Caregiver involvement in an intervention has a similar, and at times greater, effect on child outcomes compared to interventions delivered by clinical practitioners alone.

7. The intervention supports participation in mainstream and community

Every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. Natural learning environments contain many opportunities for all children and families to engage, participate, learn and practice skills. Children on the autism spectrum and their families may require additional supports to participate in community life. This support can be provided through the child's informal supports, community and mainstream supports and funded supports in an NDIS plan. For example a family may need support to be able to understand the best communication approach for their child and this in turn enables them to explain to others around the child how best to approach communication. This can then enable the family to feel more confident accessing community and sharing care with others around the child, such as grandparents taking the child to a community event.

Sometimes there is a need to develop the capacity of the child and family at the same time as developing the capacity of the environments around the child. For example working with a community setting to understand the needs of an autistic child and what they may be able to reasonably adjust to enable children on the autism spectrum to participate in an activity. Some recent examples include football clubs developing sensory spaces to enable a child on the autism spectrum and their family to attend a football match and supermarkets offering a low noise hour for shopping. The funded supports in an NDIS plan should not inadvertently reduce a participant's community or mainstream participation and/or should not duplicate supports that are available in community and mainstream settings.

Where there are indications that a child will be reducing or withdrawing attendance in mainstream settings, for example education, it is important to understand the reasons for this and the supports that were or could be available to maintain attendance. Professionals, the child and family should work together to identify barriers, review any interventions that have been trialled and outcomes and what reasonable adjustments have been or could be

applied. For some mainstream services the child may be eligible for mainstream inclusion supports, for example, State or Commonwealth funding for childcare or preschool settings.

Recap of the seven key principles:

1. The intervention is based on a good understanding of autism
2. The people who deliver the intervention know the person well and respect their feelings and views
3. The intervention is adapted to the needs of the person receiving it
4. The intervention is based on a theory that is logical and scientifically plausible
5. The intervention works in the real world, not just in a research laboratory
6. Research evidence shows the intervention can work for people on the autism spectrum
7. The intervention supports mainstream and community participation

6.2 Standards for the delivery of autism interventions

We have identified 7 standards for how therapy and supports for children on the autism spectrum should be applied. This section sets out further information on these standards and why we think they are important.

1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals

Where the intervention is delivered by professionals, it is important that they have the appropriate qualifications to deliver the intervention effectively. For example, in Australia many allied health professionals are registered under the National Registration and Accreditation Scheme (NRAS) for health practitioners. This scheme is the primary source of certification for health professionals in Australia, providing registration for all medical and nursing professionals as well as some allied health professions.

The NRAS is maintained by the [Australian Health Practitioner Regulation Authority \(AHPRA\)](#) and aims to ensure that only suitably trained and qualified practitioners are registered. This registration tries to ensure that allied health professionals follow best practice, such as using evidence-based interventions.

It is important that, in addition to any professional training, professionals have an appropriate level of experience, that is, they have actually worked successfully with children on the autism spectrum. It is equally important that they have the right attitude, that is, they 'get' autism and they 'get' children on the autism spectrum and work very closely and in equal partnership with the child, parent and carer.

2. The people delivering the intervention follow established guidance

The people delivering the intervention should follow established guidance, especially when that guidance has been published by relevant regulating bodies or is based on research

evidence. This also applies where the interventions are not specifically covered by regulating bodies.

For example, in Australia the [Department of Social Services](#) guidance on interventions for adults on the autism spectrum and for children and young people on the autism spectrum. The Autism CRC [narrative review](#) updates and builds on this earlier study.

It is also helpful if the people delivering a specific intervention follow any guidance (usually set out in the form of a manual of instructions) from the developers of the intervention. This guidance will normally explain the key principles behind the intervention and how it should be delivered. Following the guidance ensures that the intervention is actually delivered in the way it was intended.

3. The intervention provides significant benefits

Interventions should provide significant benefits to children on the autism spectrum (and their family or carers). The research highlights that the most effective and safe interventions are those that are well researched, are evidence based and have measurable outcomes that can demonstrate the effectiveness and benefits of the intervention. Interventions should be based around the core characteristics of autism, be able to be related back to skills and development, build capacity and have the child and family at the centre as equal partners.

For example a recent study of weighted blankets reported that a weighted blanket ‘did not help children on the autism spectrum sleep for a longer period of time, fall asleep significantly faster, or wake less often. However, the weighted blanket was favoured by children and parents, and blankets were well tolerated’.

In other words, the researchers did not think that the weighted blankets provided any significant benefits but the parents did and wanted to keep them. This may be because the parents saw some changes in the child that the study was not measuring, such as making the child calmer. Or it could be that the parents thought they saw some benefits that were not actually there. The choice of the weighted blanket in this instance becomes an everyday expense not something considered as a reasonable and necessary NDIS funded support.

Some interventions have not yet shown long-lasting benefits. For example, some treatments (such as oxytocin, a hormone that is injected or inhaled) have shown improvements in behaviours and communication skills, but only for a brief period after the treatment was given. When the treatment is stopped, the measured improvements in behaviour are lost.

4. The intervention is carefully monitored and reviewed on a regular basis

All interventions should be carefully monitored and reviewed on a regular basis to ensure that the intervention significantly advances the individual towards agreed intervention goals and outcomes.

If it becomes clear that there are no significant benefits, the intervention should be stopped or amended.

5. The intervention does not cause significant physical or emotional harm

Some interventions have a major risk of physical or emotional harm. For example, holding therapy is a type of attachment therapy. It is forced holding by a therapist or parent, either until the child stops resisting or until a fixed period has elapsed. The carer does not usually release their hold until the child 'surrenders' and looks into the carer's eyes. The carer then returns the child's gaze and exchanges affection.

This therapy involves deliberately provoking distress in children. The American Psychological Association recommends that holding therapy shouldn't be used because of the potential risk of harm and absence of evidence that it benefits children.

Holding therapy is a good example of an intervention which can cause physical harm, as well as emotional harm through the act of forcing a child to 'surrender.'

6. The benefits outweigh any costs (including risks)

Weighing up any potential costs (including any risks) against any potential benefits for an intervention is important, as some people may be willing to take on more risk than others.

Some interventions may present significant costs and side effects. For example, the intensity of a therapy needs to be weighed against the potential high costs and associated challenges, such as family stress and coping. Another example is the use of tech-based therapies. In these instances the benefits of technology-based interventions such as apps, needs to be weighed against the challenges that may be associated with increased screen time and transitioning off screen time.

7. The intervention is good value for money and time invested

One of the main goals of early intervention is to provide an appropriate amount of support as soon as possible so that children on the spectrum and their families are able to maximise the benefits provided. Different people will have different ideas about what this means. Some interventions are expensive and it is important to identify as many of the costs as possible before undertaking the intervention to ensure both value for money, time invested and the outcomes achieved.

Clinicians and service providers can provide guidance and at times may believe that it is appropriate to recommend only one type of therapy to parents. Some therapies are intensive and requires significant participation by multiple caregivers and educators of a child to be effective and at times requires a higher funding level that does not always provide greater outcomes or value for money when compared to alternatives. For example there is variation with some providers or professionals recommending 20 hours of clinical based interventions whilst others recommend a similar amount of hours but delivered through a mix of a clinical and natural settings. There was insufficient evidence in the Autism CRC research to determine whether particular delivery characteristics (e.g. individual or group delivery; clinic, home or school setting, face to face or tele practice) may maximise the effects of an intervention and, if so, for which children.

Recap of the seven standards:

1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals
2. The people delivering the intervention follow established guidance
3. The intervention provides significant and lasting benefits
4. The intervention is carefully monitored and reviewed on a regular basis
5. The intervention does not cause significant physical or emotional harm
6. The benefits outweigh any costs (including risks)
7. The intervention is good value for money and time invested

7. Informing reasonable and necessary supports

Up to this point, we have provided you with an overview of how the Autism CRC research, other research and best practice has informed principles and standards for early interventions for children on the autism spectrum. In this section we are proposing how we will use this informed framing, current data and previous autism investments to develop a funding framework to inform our decision making in accordance with the NDIS Act. This includes the type and level of early intervention supports included in a plan for a child on the autism spectrum.

It is important to remember when we are talking about funding levels it relates to capacity building early intervention. NDIS plans may also have additional funding for personal care, supports to sustain informal supports (sometimes called respite) and assistive technology. This is currently contained in a participant's core supports budget.

We are also sharing the indicative levels of funding. These are called indicative levels as this process and your feedback will help us to finalise them. This section provides explanations as to how we have arrived at these levels. It is important to note the levels are reflected as ranges and this acknowledges that each child is individual, autism is a spectrum and capacity building needs will change overtime.

In this section you will find links to case studies that are designed to demonstrate how the NDIA applies reasonable and necessary.

7.1 Our legislative decision making

Short term early intervention - Many children on the autism spectrum will benefit from short term early intervention that is delivered through our early childhood partners and may never need to become participants of the Scheme. Short term early intervention is aimed at increasing the child and family's learning and development to enable them to actively participate in everyday activities within their natural settings. These supports might include access to information, provision of strategies, family based education, therapy, parenting

participate in everyday activities within their natural settings. These supports might include access to information, provision of strategies, family based education, therapy, parenting support, service planning and access to the community. Short term early intervention is generally up to twelve months. If the child develops more severe and persistent functional impacts they may access another period of short term intervention or may at that point be supported to test NDIS eligibility.

Scheme participant - For those children that do become participants, the NDIA is required to make decisions about the reasonable and necessary supports and level of funding in a participants plan in accordance with the NDIS Act. Based on the Scheme's insurance principles and approach to early intervention, it is intended that the principles and standard for autism early interventions, outlined in Section 6, will be used to assist us in making those decisions. For the purposes of this consultation we are focusing on the levels and types of support for early intervention designed to build the capacity of children on the autism spectrum. This is distinct from any additional funding that may be included in a child's plan for other supports, such as personal care, respite and assistive technology.

The reasonable and necessary level of funded supports in a child's plan for early intervention supports are based on the functional capacity of a child, including the impact of their environment, and their individual circumstances, such as the level of informal support and access to community and mainstream services. This information is currently collected in various ways throughout the access and planning process. The NDIA is currently consulting on reforms that will make the collection of this information more streamlined and consistent. This will ensure our decisions are more fair and equitable for all participants.

The NDIA is currently required to determine funded supports by considering each individual support and whether it meets the reasonable and necessary criteria under section 34 of the NDIS Act and Rules.

The **NDIS legislative considerations include**, whether:

- the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations
- the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation
- the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support
- the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice
- 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
- the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered: (i) as part of a universal

service obligation or; (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

There are **situations where we will not fund** an early intervention support or require further evidence of the potential outcome. This may occur when:

- more than one provider is engaged and their recommendations overlap or duplicate supports. For example:
 - the parents of a child with a goal to increase the range of foods they eat gets support from an early intervention team to support the child to participate in family mealtimes and
 - an individual speech pathologist is also supporting the family to introduce different foods and textures.

The different strategies could work inadvertently against each other causing possible confusion for the family and child.

- a provider's goal and a child's goal are different and do not align. For example the child and parent want to use interventions to support building capacity in natural setting and the providers goals are based on practicing interventions in a clinical or closed environment
- the proposed support would not be provided by a qualified/accredited person or organisation. For example speech and language interventions provided by someone who does not hold a degree in Speech Pathology and is therefore unable to be a member of Speech Pathology Australia
- there is weak or no evidence that the intervention will support an increase in developmental or functional skills, independence or social participation. For example an intervention has been in place for 12 months and there has been no capacity building gains
- there is no evidence that the support will increase the child's participation in mainstream and community settings or the child is being withdrawn from educational settings to receive supports
- the request does not take into account the role of informal supports and parental responsibility
- there is no evidence that the support will build the family's capacity
- there is evidence that the support could be harmful or impact on the rights of the child.

There will be instances where we will not agree with the parents request or provider recommendations for intensive capacity building supports. This may occur where recommendations do not consider the principles relating to plans (NDIS Act s.31) and the reasonable and necessary criteria (NDIS Act s.34).

You can find a case study on swimming lessons that looks at building community inclusion in [Appendix One](#)

Later in 2021, our approach to funded supports are proposed to change. As outlined in our [Planning policy for personalised budgets and plan flexibility consultation paper](#) a participant's

plan will include a budget that has much more flexibility and choice and control for participant's and their families over the supports they choose to use.

The early intervention funding levels outlined in this report are intended to apply to existing reasonable and necessary decision making processes. They will also inform the development of personalised budgets for application under the new planning policy later in 2021.

7.2 Our existing support levels

The NDIA routinely monitors the number of participants and levels of supports provided to NDIS participants. Data and information on performance is reported in the Quarterly Report to Disability Ministers.

As at 30 December 2020, there were around 137,000 participants on the autism spectrum, including around 80,000 children aged under 13 years. The current NDIS average capacity building budget for children aged under 13 years with autism as their primary disability is \$10,700.

Currently there is an inconsistency in capacity building budgets and utilisation. We can see that people who live in higher socio-economic areas receive higher budgets on average. There is also an emerging trend of requests for funding for similar levels of interventions or increased hours where there is little or no evidence of the intervention increasing the family or child's capacity or adjustments. We can see some reduction when children start attending an education setting but this too is varied. This all appears to have no relation to a child's functional capacity.

Because the Scheme is built on insurance principles we would expect to see a reduction in funding as a participant's capacity increases.

For example, a two year old child entering the Scheme may require a higher level of funding for initial interventions. Over a cycle of three plans as the early intervention is building and maintaining, capacity funding alters accordingly. Whilst this example shows progressive reductions there may be times that a the child needs an increase in the next plan cycle such as an emerging new function impact, change in social and environmental situations or transitioning to school:

First Plan	\$25,000
Second Plan	\$15,000
Third Plan	\$ 8,000

This generalised example equates to \$48,000 funding, for capacity building, over a three year period or an average of \$16,000 per annum.

7.3 Previous support provided

We have considered historical funding arrangements for comparable early childhood and early intervention services that existed prior to the NDIS.

The **Helping Children with Autism (HCWA)** program provided families of children with an eligible diagnosis with access to early intervention funding up to \$12,000 (up to \$6,000 per financial year) until children turn seven years of age. The funding supported delivery of multidisciplinary evidence-based early intervention to facilitate improved cognitive, emotional and social development, including through one-on-one activities and tailored group and individual programs. Families accessed support through a panel of providers approved by the Australian Government and the [Early Intervention Service Provider Panel Operational Guidelines](#) provided the operational framework for service provision. The HCWA program also included information and support through a variety of sources to assist families in their decision making. All eligible children receiving individualised HCWA funding are transitioning to the NDIS and the program will close on 31 March 2021.

State/Territory funded ECI services also supported children on the autism spectrum through the state early childhood education and disability systems. Quality approved providers supported children through best practice approaches from one hour to 8 hours per week. Most children were supported through both specialist supports and to access a broad range of early childhood development services provided through a broad range of Commonwealth and State funded programs.

The **Autism Specific Early Learning and Care Centers (ASELCC)** provide early learning programs and specific support for children aged zero to six years on the autism spectrum or with autism-like behaviour in a long day care setting. They also provide families with education and support to use early intervention strategies in the home to maximise the positive impact on children's long-term outcomes. The long day care model allows parents the opportunity to participate more fully in education, employment and the community. This model is individualised and can bridge group based and individualised early intervention programs, supported mainstream participation and supported child care that has a focus on facilitating successful transition to school. All eligible children attending an ASELCC are transitioning to the NDIS and children now enrolling in ASELCCs need to fund their place through their NDIS plan or privately. Each ASLECC center has a different delivery model which results in differing cost structures and differ minimal days attendance.

7.4 Our proposed funding framework for early intervention for children on the autism spectrum

Where a child on the autism spectrum becomes a participant, there are considerations that impacts the level of funding for early intervention supports included in their plan. These build on existing early childhood intervention principles and are evidence and research based:

1. Translating the known evidence base into a funding framework and practice guidance

The NDIA commissioned research, through the Autism CRC, is a combination of the best available scientific evidence underpinning early intervention for children on the autism spectrum. While this paper provides a scientific foundation for developing practice guidance, the NDIA recognises this is one step towards strengthening evidenced informed information and approaches.

In the development of a funding framework the NDIA has sought to support evidence informed practice and to 'operationalise' the science, by further incorporating the voices of consumers and experienced clinicians / professionals.

The current suggested funding amounts balance the knowns and unknowns. Through the release of this consultation paper we are taking the next step to supporting children on the autism spectrum and their families through a framework that brings this together.

Future steps towards 'operationalising' the science is to continue to develop other information based on the existing research, such as participant decision making guidance, continue to understand and grow evidence based research and gather the appropriate data to improve our knowledge and understanding of best practice and support for children on the autism spectrum and their families. This is in the understanding that early intervention and support for a child's development is not the sole responsibility of the NDIS.

2. Holistic planning

Holistic planning considers the full environment of the child and family which includes all of the supports that are available to the child and family. All early childhood intervention supports must be connected and interrelated to the child's life and in the context of the families/care giver role. A child on the autism spectrum can access many areas of support in their life including health, early education services, community based supports and school. We recognise that NDIS is one of those supports. A holistic plan will map out goals and aspirations, and detail NDIS funded elements, funded elements and non-funded elements including parental responsibility, school and early childhood services.

The NDIS legislation is clear that the NDIS should not fund supports that are the role and purpose of other funded systems or what is reasonable to expect families, carers, informal networks and community to provide (NDIS Act s.35 and s.36).

All proposed funding ranges, later in this document, assume the requirement for support to develop a holistic plan upon entry to the scheme. This is undertaken by an Early Childhood Partner or the NDIA. In the context of this paper holistic planning occurs after access is met and is an initial assessment of an individual's strengths, challenges, goals, and preferences and is critical to developing intervention targets that are meaningful to the child and family. If a child has been receiving supports from an early childhood early intervention partner prior to meeting access they may already have a holistic plan in place. Holistic plans will include connections to health and early education services, outline the types of interventions, the

role of all professionals and the family, care givers and support for all settings (for example centre based, home based, natural settings).

3. Outcomes focused - as capacity is built, professional supports reduce

Early intervention is all about giving children with disability, and their families, supports to enable the child to have the best possible start in life. Through early intervention children, their families, can get specialised supports and services. These services aim to promote the child's development, the family and child's wellbeing, and the child's participation in their community. We know that early childhood years are critical. They set the foundations for how children learn and develop. We want to support children and their families early to improve their outcomes later in life and reduce dependence on professional supports in the longer term.

As children and families develop new skills and functional ability, their need for supports will generally decrease. This may lead to a reduction in their NDIS plan as they develop new skills, enter the education system and experience more inclusion. Families and other adults in the child's life will be able to support the child's development with reduced dependence on funded supports as helpful strategies and opportunities for practice becomes part of daily life. Being included in everyday activities gives children with disability the same opportunities as all children. It may help them to develop friendships, to interact with others and be a part of their community.

Early intervention approaches are designed to build capacity for both the child and the family. In a child's first NDIS plan, capacity building supports will typically be higher in recognition of the importance of this early investment. Initially early intervention will focus on supporting families to understand their child's disability and get to know the child's strengths and interests.

Planning cycles enable the child, family and us to consider any new and emerging needs.

You can find an example in Appendix One that explains outcome focus – as capacity is built, professional supports reduce.

The research highlights that the most effective and safe interventions are those that are well researched, are evidence based and have measurable outcomes that can demonstrate the effectiveness and benefits of the intervention.

4. Lifespan approach

It is not unusual for a participant's funding to vary from plan to plan, as their situation changes. Dependant on the functional impacts of a child on the autism spectrum we would expect to see changes in goals and aspirations as the child receives positive benefits from early intervention and there are changes in the interventions and systems from which they require support. For example, commencing primary or secondary school, a person's capacity grows or diminishes, and one-off capital items such as assistive technology to improve functional capacity may be required. This reflects a lifespan perspective and family centred approach, considered to be best practice in early intervention.

Support may be required by the participant in early childhood settings (for example, preschool or childcare) and to support transition to primary and secondary school, noting that the funded supports in an NDIS plan should not inadvertently reduce a participant's community or mainstream participation and/or should not duplicate supports available in community and mainstream settings, such as within schools. When children start school, the amount of time that they spend at home is reduced.

As an example on how things may change across a lifespan, across Australia the education system has a role in supporting children at school by making reasonable adjustments so that students with disabilities have the same opportunities as their peers, which includes capacity building. This may look like using visual timetables so that the child knows what work is coming up, or accessing school support services like psychologists, speech pathologists and visiting teachers.

The NDIS remains responsible for supports for children at school such as personal care and support with eating and drinking. The education department is responsible for providing support for a child's learning, including: teaching, learning assistance and aids, school building modifications and transport between school activities. One example of this is a child going on their first school camp. The NDIS may fund assistance with developing and implementing strategies to practice at home to prepare the child for the experience. The education system would fund additional support to enable the child to participate at the camp.

You can find a case study in [Appendix One](#) that explains Lifespan approach – Transition to high school.

Recap of the funding framework:

- Translating the known evidence base into a funding framework and practice guidance
- Holistic planning
- Outcomes focus - as capacity is built, professional supports reduce
- Lifespan approach.

7.5 Proposed levels of funded support for autism early intervention

The intent of NDIS early intervention is to identify and provide effective early intervention support. This includes for children and young people with developmental delay (under 6 years) or disability. A key focus is to build the child and family capacity in daily activities and everyday settings.

We are proposing four funding levels based on the functional capacity and assessed needs of a child, reflecting all we know at this stage.

There are two tables one for children 0-6 years of age and one for children 7-12 years of age. Each level is a range with participants on average receiving around the middle of the range, and only a small amount of participants expected to receive the top of the range. This

There are two tables one for children 0-6 years of age and one for children 7-12 years of age. Each level is a range with participants on average receiving around the middle of the range, and only a small amount of participants expected to receive the top of the range. This is based on each situation being unique and some children being in a more intense phase of intervention, a life transition point and others at more a maintenance phase.

The indicative funding levels and suggested frequency of support are based on a holistic approach that also considers community inclusion, participation, non-funded and funded interventions.

Autism is usually diagnosed by trained health professionals, who undertake a medical assessment and observation of certain characteristics such as social communication, behaviours and intense or focused interests. When determining funding we seek to understand the reduced functional capacity of a child and their family related to autism and how this impacts on managing tasks and activities in everyday situations. We look at both strengths and reduced capacity.

As defined in the [Independent Assessment Framework](#), “Functional capacity refers to an individual’s ability to be involved in life situations and to execute tasks or actions, with and without assistance (assistive devices and/or personal assistance). Information regarding impairment(s) and environmental factors, and how they impact the individual’s function is included when assessing functional capacity.”

Rather than using clinical terms we currently describe a child’s level of need as high or medium / low based on the reduced functional capacity and the level of effort required over the course of the plan.

A ‘high’ area of need may include a need for regular, frequent and sustained early intervention supports over the duration of the plan. A ‘medium / low’ area of need may include shorter bursts of early intervention support followed by occasional reviews.

In establishing these indicative levels we recognise each child and family are individual with their own needs and capacity building needs will change over time. Determining the levels of indicative funding includes considerations with regards to development and functional impacts of autism characteristics including social communication, restricted and repetitive interests behaviours and sensory behaviour. Consideration is also given to related skills and development opportunities including but not limited to: communication, expressive language, receptive language, cognition, motor, social-emotional and challenging behaviours, play and adaptive behaviour. Other considerations include family wellbeing including supporting the development of caregivers and interaction strategies and social and environmental needs. Where one area of need may be impacting on another areas for example, significant language and communication delays may have an impact on social and emotional development areas, this is also taken into account.

When considering early intervention capacity building, the Agency works with the child and family to understand:

What is the level of impact of the child's disability on their functioning in everyday routines?
What is the level of effort required to support the child's development (capacity building)?

We recognise that there may be a small number of children who require some further consideration due to other factors, for example, where they may have multiple disabilities or significant behaviours of concern.

We consider the four levels of early intervention funding proposed in [Table 2](#), are sufficient to provide quality early intervention outcomes while ensuring opportunities for participation and inclusion in family and community life. These levels are based on building on the child's strengths and interests towards functional outcomes rather than the specific models of available intervention programs. Where there is evidence that families have additional needs to sustain their caring roles or support the disability related in-home support needs for the child, these may be funded through core supports rather than capacity building.

Indicative capacity building funding levels:

- provide a range based on functional capacity and need and are reflected as annual figures
- are intended to indicate the range rather than exact amount of funding. For example, not every child under 6 years of age in level one will receive \$8,000 when their indicated level of support falls within the range of \$4,000 - \$8,000
- are shown as 0-6 years of age and 7-12 years of age reflecting that as a child reaches 6 or 7 years of age they will enter the education system and that education system has responsibilities related to supporting the child's learning. If the child requires supports such as personal care at school this will be reflected in core supports in the NDIS budget not in capacity building
- reflect capacity building, for community settings and the child, to enable community participation
- can be used flexibly, the child and family can choose to use capacity building early interventions in an individual or group based setting or a mix of both
- are based on the sum of hours of support from the NDIS price guide:
 - there is some pricing variance across states and territories for some supports
 - in some circumstance service providers may deliver supports at rates below this guide and families in acting as informed consumers in the NDIS market may be able to gain greater utilisation of their NDIS funds.
 - parents and families may choose to use their funds in different ways such as a mix of individual and group activities to access more interventions.

You can find a case study in [Appendix One](#) that explains Capacity building supports - funded and non-funded supports

Table 2 - Indicative level of funded support: children on the autism spectrum under 7

Indicative Level	Functional Impact	This may look like a child with	Supports
<p>Level 1 \$4,000 - 8,000</p>	<p>One high area of need</p> <p>One medium-low area of need</p>	<ul style="list-style-type: none"> • A high area of need with their language and communication related to the rate, rhythm and pitch of their speech and the impact of this on social communication and daily life. • A low area of need in repetitive behaviours such as pacing and rocking. 	<ul style="list-style-type: none"> • May benefit from higher intensity interventions for 6 – 12 weeks. • Typically professional interventions would reduce to fortnightly. • May benefit from one visit per term to childcare, preschool/ kinder or school.
<p>Level 2 \$8,001 - \$12,000</p>	<p>One high area of need</p> <p>2-3 medium-low areas of need</p>	<ul style="list-style-type: none"> • A high area of need related to sensory behaviours such as avoidance of smells and sensations and only wear certain fabrics. This impacts on their self-care skills and daily life such as meal times, dressing, bath time, not yet toilet trained. • Further medium to low areas of need, for example, with language development (articulation) and physical development (fine motor - use of utensils, pencil skills, manipulation of fasteners). 	<ul style="list-style-type: none"> • May benefit from higher intensity interventions for 6-12 weeks • Typically professional interventions would reduce to a mix of weekly and fortnightly • As new capacity is built may have a second intensive period to target a new area may be indicated • May benefit from one visit per term to childcare, preschool/ kinder or school.
<p>Level 3 \$12,001 - \$30,000</p>	<p>Two high areas of need and possibly 1-3 areas of low need</p>	<ul style="list-style-type: none"> • High areas of need in cognitive development and social skills. This might look like difficulty following routines and instructions at kindergarten and home, avoidance of new tasks, impulsive, avoids craft activities, has narrow interests in play activities and unaware of safety and looks to escape. 	<ul style="list-style-type: none"> • May benefit from higher intensity interventions for 6-12 weeks. • Typically professional interventions would reduce to a mix of weekly and fortnightly. • As new capacity is built may have a second intensive

Indicative Level	Functional Impact	This may look like a child with	Supports
		<ul style="list-style-type: none"> This child may not have a friend, often plays on his/her terms and other children may avoid them. The child may have further medium to low areas of need, for example, with emotional development (learning to name own feelings and use calming strategies). 	<p>period to target a new area may be indicated.</p> <ul style="list-style-type: none"> May benefit from more than one visit per term to childcare, preschool/ kinder or school.
<p>Level 4 \$30,001 – \$35,000</p>	<p>Three high areas of need with possibly; 1-3 medium-low areas Identified, or equipment needs identified</p>	<ul style="list-style-type: none"> A high area of need with language and communication development: can request basic needs, cannot take more than one turn in conversation, can follow one step instructions. A high area of need with social skills development: plays alone, limited interest in others. A high level of need with emotional development: frequent tantrums, obsessed with iPad, hits out at sibling. May have further medium to low areas of need with self-care (wakes through the night, meal times, does not like bath time and brushing teeth). 	<ul style="list-style-type: none"> May benefit from some initial interventions to establish priority areas and daily routines Typically professional interventions be a mix of weekly and fortnightly May benefit from more than one visit per term to childcare, preschool/ kinder or school.

When a child enters the education system things change

Children will generally enter the education system at around five years of age. The role of the education system is to support a child's learning. You can find out more about this in the [Applied Principles and Tables of Support](#).

In the years after a child starts school, the capacity building in plans will reduce, this is due to them entering another system. This change in funding reflects children having developed new skills (built their capacity), having gained experience from more inclusion, spending less hours in the home and enables down time with families and friends outside of school hours.

Table 3 - Indicative level of funded support: children on the autism spectrum 7 to 12 years²

Indicative level of funded support	Functional Impact	This may look like a child with	Supports
Level 1 \$2,400 - \$4,800	One high area of need One medium-low area of need	<ul style="list-style-type: none"> • A high area of need with their language and communication related to the rate, rhythm and pitch of their speech and the impact of this on social communication and daily life • A low area of need in repetitive behaviours such as pacing and rocking. 	This may include one visit to school per term and up to 24 hours of professional intervention that can be used flexibly across the year.
Level 2 \$4,801 - \$7,200	One high area of need 2-3 medium-low areas of need	<ul style="list-style-type: none"> • A high area of need related to sensory behaviours such as avoidance of smells and sensations and only wear certain fabrics. This impacts on their self-care skills and daily life for example, meal times, dressing, bath time, not yet toilet trained. • Further medium to low areas of need, for example, with language development (articulation) and physical development (fine motor - 	This may include one visit to school per term and up to 36 hours of professional intervention that can be used flexibly across the year.

² This table includes the same characteristic and impact descriptors as table one

Indicative level of funded support	Functional Impact	This may look like a child with	Supports
		use of utensils, pencil skills, manipulation of fasteners).	
Level 3 \$7,201 - \$18,000	Two high areas of need and possible 1-3 medium-low areas of need	<ul style="list-style-type: none"> • High areas of need in cognitive development and social skills. For example, repetitive behaviours and restricted interests such as difficulty following routines and instructions at kindergarten and home, avoidance of new tasks, impulsive, avoids craft activities, has narrow interests in play activities and unaware of safety and looks to escape. • This child may not have a friend, often plays on their terms and other children may avoid them. • The child may have further medium to low areas of need, for example, with emotional development (learning to name own feelings and use calming strategies). 	This may include one visit to school per term and up to 90 hours of professional intervention that can be used flexibly across the year.
Level 4 \$18,001 - \$21,000	Three high areas of need with possibly; One to three medium-low areas identified, or equipment needs identified	<ul style="list-style-type: none"> • high area of need with language and communication development (can request basic needs, cannot take more than one turn in conversation, can follow one step instructions), • high area of need with social skills development (plays alone, limited interest in others) and emotional development (frequent tantrums, obsessed with iPad, hits out at sibling) 	This may include one visit to school per term, and up to 105 hours of professional intervention that can be used flexibly across the year.

Indicative level of funded support	Functional Impact	This may look like a child with	Supports
		<ul style="list-style-type: none"> may have further medium to low areas of need with self-care (wakes through the night, meal times, does not like bath time and brushing teeth). 	

It is important to remember that the NDIS does not approve funding based on specific ‘programs’ but rather, considers the evidence that a level of capacity building supports is required and expected outcomes. Based on legislation, available information and evidence we determine the level and reasonable and necessary supports required to support the child and their family in pursuit of the child’s goals. The family then determines how and who to engage with for early intervention.

8. Implementation considerations

8.1 Participating in the planning process

We rely on information from the participant, providers, family and carers to support the planning process. This is important so that the child and families understand the level, type and frequency of interventions. If the child has already been receiving interventions or therapy supports we will want to see the outcomes and impact of these supports and recommendations for ongoing support. This may need to be provided by multiple providers and the outcomes will need to consider the child and families reflections and linkages to goals and aspirations. We will be interested in the mode and intensity of any current supports, how long they have been applied for, what have been the positive functional outcomes to date and what have been the barriers and any proposed mitigations.

If the child has a recent diagnosis or this is the first time they are seeking support, baseline assessments will be used to inform the development of a holistic plan.

Families will be helped to navigate the system, trial interventions and understand choice and control when considering providers. Occasionally, for a first plan, where a trial of various interventions is indicated or where there has been limited evidence of outcomes from existing interventions, a shorter plan may be developed.

8.2 Improving participant choice and control

The NDIS is grounded in principles of participant choice and control over the services and supports participants need to meet their needs and pursue their goals. Once a plan is finalised and budget allocated, children, families and carers are able to negotiate with their provider on the frequency and pattern of supports within their available funding. This can often involve children, families and carers trying a number of different interventions to understand what works best for their child to build their capacity and improve their language, social skills and behaviour.

To understand different interventions and whether and how a provider is applying best practice some questions families and carers could ask include:

1. What does the intervention include? How much time will be involved?
2. How long have you been delivering the intervention? What is your expertise in this area?
3. What improvements have you seen in children you've been working with?
4. How will you follow progress of my child? How will you update us on progress? How will our reflections on progress be included?
5. How much will we (family and carers) be involved in learning and practicing the interventions?
6. Will you provide us with training or guidance?

It is important to note that funds for some autism early intervention supports will be set aside as fixed amounts in a plan. Funds in the fixed budget are allocated for a specific purpose or support, which means they cannot be used for anything else. This will be particularly relevant for high cost interventions and/or where there are known barriers to achieving outcomes.

Currently budget categories are core, capacity building and capital budgets, with multiple sub-categories and complex restrictions on usage.

Proposed reforms to NDIS planning processes will further enhance participant choice and control by improving flexibility in how plan funding is used. This means a participant's funding will be divided between a fixed and a flexible budget with the budget being flexible wherever possible. This means that as future reforms are implemented, in many cases, the funds for autism early intervention supports will form part of an overall flexible budget, rather than being individually identified and costed as an aggregate of units / hours of intervention.

Participants will discuss with us, their families, carers and other supporters what they want to use their flexible funding for, but will not be required to seek approval from us for each individual decision made when implementing the plan.

This makes it important both now and when these reforms are introduced for the NDIS to support children, families and carers to recognise and understand best practice.

We recognise these improvements will require participants their families and carers to adapt and we want to improve the information and support available. We will support children, families and carers to make informed decisions, including through enhanced plan

implementation guidance. This guidance will include information about the types of interventions available and the proportion of flexible funds they might consider using for particular categories of support. Children and families will also be supported to understand the cost of autism early intervention supports they may wish to buy and best practice so they can gain the greatest value for money and outcomes for their children from their total NDIS budget and other resources, taking into consideration their needs, preferences, goals and aspirations.

Plan implementation support will also be provided by early childhood partners, local area coordinators or support coordinators (for participants with more complex needs). Plan implementation support will be adjusted depending on the complexity of the plan and the newness of diagnosis to ensure supports are tailored to each child and their family's individual needs and preferences.

8.3 Addressing conflicts of interest

By improving available information for family and carers on autism early intervention evidence, best practice and NDIS reasonable and necessary decision making, children, families and carers become more informed consumers.

We recognise that when a child is first diagnosed families can be reliant on relationships with existing professions in their child's lives. This may include seeking for them to recommend interventions and guide decisions and choice. In some locations (remote and very remote locations) children, families and carers have little choice but to take the advice of a provider who assesses their child, assists with implementation and may also provide the early intervention.

We recognise the importance of trusted relationships but also that this can create the potential for conflict of interests (real or perceived) where a provider could make recommendations in the interest of their business rather than in the best interests of their child. A participant's chosen service provider or practitioner is both a supplier of information and advice, as well as the provider of supports. There can be a conflict of interest (real or perceived) if the provider has undertaken the diagnostic assessment and intends to deliver supports to the child/family. Where this is the case, families may not have a full and balanced understanding of the options available for their child.

The role of the NDIS Quality and Safeguards Commission is to ensure that service providers comply with requirements under the NDIS Act 2013 and associated Rules. Including the NDIS Code of Conduct and, if relevant, NDIS Practice Standards that set out how real or perceived conflicts of interest can be avoided or mitigated.

9. Consultation questions

We are working to finalise the Agency's guidance on early intervention reasonable and necessary funding of interventions for children on the autism spectrum. We are committed to working with people with disability, their families and care givers, and the disability community and other stakeholders to get these changes right.

We value your feedback on the following questions. You can respond to all of them or just a few. We welcome any feedback on the positions outlined in this paper.

You are able to provide feedback via an online 'submission feedback form' on our [website](#).

We cannot respond to individual submissions.

Promoting best practice

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

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies
- None of these

2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?
3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of "holistic planning" is included in [Section 7.4](#). How can we help families to find and connect with other supports outside of NDIS?

Reasonable and necessary

4. 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 ([Section 6.1.](#)) Is there anything you would like to add?
5. 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 ([Section 6.2.](#)) Is there anything you would like to add?
6. "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”?

7. Do you have any other feedback about how we explain “reasonable and necessary?”
8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum ([Section 7.5.](#)) Do these table/s clearly explain the indicative levels of funded supports?
9. Do you have any other feedback about how we explain the indicative levels of funded supports?
10. 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?

Supporting parents and carers to exercise choice and control

11. 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?
12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

Conflicts of interest

13. 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?

Appendix One – Case Studies

We recognise that autism is a spectrum and each child/family has their own story, these examples are designed to demonstrate how the NDIA applies evidence, best practice, principles and legislation not to demonstrate the breadth of the spectrum and its impacts on individuals and their families.

Case Study: Building community inclusion

Jenny is 4 years old and has been diagnosed with autism spectrum disorder. She has met the access requirements for the NDIS and her family are working with an Early Childhood Partner to develop a plan.

Jenny lives in the city with both her parents who are keen for her to participate in swimming lessons with her peers. They have enrolled her in a local swim school where her friend Jasmin also attends.

Jenny

Jenny becomes agitated during group swimming lessons. Her sensory sensitivities and communication challenges cause emotional and behavioural distress. This is disruptive to the others in the class, and is upsetting for Jenny's parents.

Parents

Jenny's parents have requested the NDIA consider:

- cost of weekly private lessons
- a support worker to attend swimming lessons.

Swim school

The swim school have no experience with teaching a child on the autism spectrum. They are keen to learn how best to support Jenny and other children with autism.

Reasonable and necessary considerations

Is the support request solely and directly a result of Jenny's disability needs? **Yes**

Has evidence been provided to show community and mainstream options were explored, and reasonable adjustments were made to support Jenny's additional needs? **No**

Is it reasonable to expect families or carers to provide support for a 4 year old during swimming lessons? **Yes**

Are there any barriers to the family providing this support? **No**

Decision

- the cost of private swimming lessons does not equal value for money in relation to both benefits of the support and the cost of similar supports
- private swimming lessons do not promote inclusion or create opportunities for social participation or necessarily support progress towards group lessons
- support for inclusion in swimming lessons is captured in capacity building supports
- we must also consider what families and other informal supports would usually provide.
- Jenny's plan includes funding for capacity building that can be used to:
 - access support for an early intervention provider to help build her confidence in the water
 - access support for an early intervention provider to share strategies with the swimming instructor so they can best support Jenny in swimming lessons.

As Jenny's confidence around water increases she is able to participate fully in the in group swimming lessons.

Short term outcomes

- Jenny builds confidence in the water
- Jenny is able to participate in a community setting and increases her social inclusion.

Longer term outcomes

- The swim school capacity and confidence is increased, enabling other children with disabilities to participate fully in their programs.
- The swim school may make a decision to offer a 'quiet time' program that supports social inclusion by providing reasonable adjustment to support participation by children on the autism spectrum.

Example: As capacity is built, professional supports reduced

Plan 1

- 4 years old and recently diagnosed with autism
- based on functional impacts related to challenges with communication, repetitive behaviors and preference for routines entry within the range of Level 3 support
- the family and child finds larger social settings difficult with the child often becoming upset and running away / hiding. The child is behind in development around toilet training and managing changes in routines
- the first plans focused on development of a holistic plan that captures all professional and community supports and how they intersect with the NDIA plan. NDIA goals are focused on toilet training, development of strategies and routines to support capacity building within age appropriate community settings
- to implement the plan there will be initial higher levels of professional supports, which will reduce over time as the child and parents are able to build their capacity by example starting playgroup activities to encourage social interaction with self-calming strategies implemented so that the child is able to stay for entire playgroup session and enjoys story time.

Plan 2

- 5 years old and transitioning from home to kindergarten/pre-school
- child still has a mix of needs but some capacity has been built for both the child and the family. Child's functional needs indicate the child still fits within range of Level 3 support - with a 25% increase of funding from last plan to support transitioning to school
- this plan is focused on school readiness, practicing routines, and developing skills that may be required for new tasks that may be introduced in a school environment along with safety awareness
- there is a focus on maintaining and continuing to support the child and family's community engagement
- professional intervention may look like 1-2 sessions per month, however towards the commencement of school this may increase to enable visits and familiarisation with the school environment.

Plan 3*

- 6 years old and at school
- successful capacity building from plans 1 and 2 along with starting at a mainstream school means that the child now fits in the range of level 2 supports
- the child is receiving supports and services through the education system (reasonable adjustment) to enable full participation at school
- this plan is focused on language development and fine motor skill development, in addition to what is provided by the school
- capacity building is focused on outside of school activities to enable community participation, such as soccer. Parents are able to support child to participate but require intermittent support for assistance with fine motor skill development and managing behaviours following a day at school
- this may look like short blocks of professional intervention over a 12 month period as new capacity building opportunities emerge.

Plan 4*

- 8 years old and continuing at school and no new significant functional impacts identified
- this plan sits within range of Level 2 supports - with a 50 % reduction in funding
- evidence provided demonstrates that child has improved and maintained capacity
- Child is continuing to receive reasonable supports and accessing support services through the education system
- this plan is focused on enabling social skills outside the school environment with friends (e.g. birthday parties) and is expected to have less than 4 short blocks of professional interventions over the plan duration. Professional supports are more focused on problem solving and emotional development to support increased social engagement.

Plan 5*

- 10 years old and excited about school camp. Social environment is changing for the child with opportunities for age appropriate broader and more independent activities
- still sits within range of Level 2 supports for maintenance and new skills
- child is continuing to receive reasonable supports and accessing support services through the education system
- this plan is focused on increasing the child's independence to be able to take part in a school camp, education department is providing a support worker to attend camp, and extracurricular activities that involve less parental participation
- the parents and child have identified Scouts as a new extracurricular activity, and would like some assistance with developing further independence.
- This may look like short blocks of professional intervention leading up to events such as the school camp and joining Scouts
- the education system and Scouts also continue to provide reasonable adjustment to support the child's participation

*most plans are for 12 months duration this has been accelerated for the purpose of this example

Case Study: Transitioning to High School

Aron is 11 years old and in Grade 6 at his local primary school. He has been diagnosed with high-functioning autism.

Aron is doing well in primary school, but has high anxiety about going to high school. His family is currently exploring high school options for him.

Aron

Aron is interested in schedules and has a small friendship group. Aron can be fearful of change and learning new tasks and routines. He can be obsessive about planning and draws up schedules for everything, with high anxiety around things not turning out as he had planned. Aron would like to participate in extra-curricular activities with his friends and this has been identified as a goal in his plan.

At times, impending changes such as a different teacher, or changes in his usual routine can mean Aron refuses to go to school or leave the house.

High School

Aron's parents have identified a mainstream school that has experience with students on the autism spectrum. The school Aron's parents have identified means Aron would need to catch public transport as it is not close to the family home.

Parents

On further discussion with Aron and his family it was identified that Aron and his parents have already held an initial meeting with the school.

Aron's parents have requested NDIA consider:

- a support worker to attend additional high school transition sessions with Aron
- ongoing support for Aron's anxiety
- public transport costs for Aron
- a mobile phone so Aron can contact them if anything goes wrong
- a support worker to assist Aron in building confidence in using public transport
- a support worker to assist with exploring extra-curricular activities.

Reasonable and necessary considerations

- Will the requested supports assist Aron to transition to secondary school and identify extra-curricular activities?
- Is the school making reasonable adjustments to support Aron's transition?
- Has Aron identified extra-curricular activities in his goals?
- Will the supports build Aron's capacity to participate in school and the community?
- Are the supports, benefits and outcomes comparative to alternative support options?

- Do the requested supports take into account what it is reasonable to expect families, informal networks and the community to provide?
- Is the support is most appropriately funded or provided through the NDIS?

Decision

Requested supports	Decision
Already agreed between school and parents	<p>Aron's existing primary school teacher to meet with his key secondary teacher.</p> <p>Aron to meet his new key teacher in the next month.</p>
Support worker to attend additional high school transition sessions with Aron	<p>Aron's occupational therapist will meet with Aron and the school before the end of the year to discuss Aron's current routines and how the school can support Aron.</p> <p>Aron's new teacher and his occupational therapist will work with Aron to develop his initial secondary school schedule to provide as much information as possible to Aron to help him prepare for the change. This will also assist the school in identifying any adjustments they will need to make to enable Aron to participate in the learning environment (reasonable adjustment).</p> <p>It would be reasonable for NDIA to fund the occupational therapist support for transition and a once a term check in. The school has demonstrated it is undertaking its responsibilities for reasonable adjustment as well.</p>
Ongoing support for Aron's anxiety	<p>Aron could access support for his anxiety through his general practitioner and a care plan.</p> <p>The NDIS can fund supports to help build Aron's self-confidence and communication skills to help him reach his goals of making friends and developing his social skills</p> <p>If it relates predominantly to schooling, support may also be available through the education department (e.g. allied health practitioners assisting classroom teachers to make adjustments to the curriculum).</p>
Public transport costs for Aron and mobile phone so Aron can contact them if anything goes wrong	<p>The cost of public transport and a mobile phone are everyday expenses and it would not be a reasonable and necessary use Aron's NDIS funding for these.</p>

Requested supports	Decision
<p>A support worker to assist Aron in building confidence in using public transport</p>	<p>To support transition to high school Aron and his parents can utilise his plan to undertake travel training to assist with familiarising Aron with the bus route he will be taking.</p> <p>This may look like a support worker assisting Aron to read the bus time tables, plan the journey, put information into his schedule and traveling with Aron on the bus route a few times to problem solve any concerns and ensuring Aron knows where to go when he gets to school and at the end of the day.</p> <p>Whilst due to other family and work commitments they cannot assist with week day training the family have said they can practice the bus route with Aron on weekends.</p> <p>Some initial support for Aron in learning to take the bus to school may also create opportunities for Aron to use public transport for getting to and from this extra-curricular activities and other community events.</p>
<p>A support worker to assist with exploring extra-curricular activities</p>	<p>A support worker for a limited period to assist Aron to trial some extracurricular activities would be supported through Aron's NDIS plan.</p> <p>Once an ongoing activity has been identified, if required, the support worker or occupational therapist can support the community group to understand any adjustments they may need to make to enable Aron to fully participate.</p>

Case Study: Capacity building supports - funded and non-funded interventions

Jackie is 3 years old and was recently diagnosed as being on the autism spectrum. She has met the access requirements for the NDIS and her family have worked with an NDIS early childhood early intervention partner to develop a plan. Jackie attends an early childhood education setting two days per week.

Jackie's family are concerned that the NDIS plan developed with the early childhood early intervention partner does not include enough funding for building their capacity to support Jackie and for Jackie to access 20 hours of intervention for at least one year. This 20 hours is recommended in some Autism literature and they are feeling stressed and are talking about having to mortgage their house to pay for more therapy themselves.

Jackie's support needs

Jackie is identified to have one high area of need, with self-care skills impacting significantly on daily life. She needs a lot of assistance at meal times and with dressing and is not yet toilet trained. Jackie also has two medium to low areas of need, including language and physical development. She needs support to explain her feelings and needs help when to use things like cutlery and pencils. Jackie's parents also need support to understand how to best support Jackie and practice any suggested interventions in these areas.

Capacity building supports in the plan

Jackie's plan is developed with capacity building supports to allow weekly visits with the key worker for the first three months of service to establish relationships, refine goals and discuss strategies. Then ongoing fortnightly home visits to monitor Jackie's progress and support the parents to problem solve any concerns, modify strategies and monitor progress as well as two visits per term to the early childhood education setting to support staff with strategies to further promote Jackie's development. Jackie's family understand that the key workers visits to the early education setting are important for ensuring the staff understand the best application and approaches for Jackie. Jackie's parents also understand that supporting Jackie to practice within natural environments such as home and community is equally as important as the application within the early childhood setting.

Implementation

The early childhood partner assists the family to engage a suitable provider who offers a key worker model with a team of allied health professionals working together through the key worker to support the family. The key worker will deliver supports in the family home and at childcare and has a skilled team of professionals supporting the family with sound evidence based strategies. The key worker supports the parents, and childcare staff to understand Jackie's goals and strategies to support her learning and development in natural settings.

Opportunities for practice per week (mix funded and non-funded)	Hours per week
Input and support from experience early childhood team through the key worker (weekly for three months and then fortnightly).	1
Daily dressing and breakfast routine implementing visual schedule, reward chart, simple prompts and other agreed strategies equals at least two hours per day of routines based early intervention in the home. (non-funded)	14
Early childhood educators work with Jackie at child care two days per week to support the use of gestures and visuals to express her feelings as well as multiple opportunities to develop fine motor skills through indoor and outdoor play and other activities of interest with her peers. (combination key worker may support capacity building of staff)	6
Jackie attends a small community dance group once a week that includes a dressing routine prior to dancing where Jackie is highly motivated to increase her independence because she enjoys dancing so much. Dancing supports her physical and emotional development in line with her goals as well as improves her wellbeing and social development. (non-funded)	1.5
Total hours of supported and intentional intervention by a combination of professionals, educators, parents and other carers who have been trained.	22.5