REIMAGINE
AUSTRALIA

# THE WHOLE CHILD, THE WHOLE FAMILY

## Supporting young children and families early, to reach their full potential

RESPONSE TO THE NDIA
INTERVENTIONS FOR CHILDREN ON THE AUTISM SPECTRUM' CONSULTATION PAPER.

SUBMISSION

MAY 2021

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## OUR ALLIANCE PARTNERS:

This submission is made by Reimagine Australia in partnership with the following organisations and individuals:

SHAPINGOUTCOMES
Here to support children thrive, connect & belong

Outcomes Therapy

scope

early start
AUSTRALIA

Playgroup Australia™

EarlyEd

kurrajong

MY THERAPY HOUSE
Opening doors in communication and relationships

Kim Bulkeley
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The University of Sydney
Centre for Disability Research and Policy

THE UNIVERSITY OF
SYDNEY

bridges for learning

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# Executive Summary

The National Disability Insurance Agency (NDIA) are working to finalise their approach to the application of reasonable and necessary decision making in relation to early intervention for children on the autism spectrum. The proposed approach is detailed in a consultation paper released by the NDIS in March 2021. Reimagine Australia (RA) welcomes this opportunity to provide feedback on the consultation paper and looks forward to participating in ongoing collaboration with the NDIA on these matters.

The NDIA have requested feedback on the consultation document in order to:

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,

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,

and,

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.

The NDIA has posed questions to gather feedback across four areas: promoting best practice: reasonable and necessary decision making; supporting parents and carers to exercise choice and control; and managing perceived and actual conflicts of interest. RA has provided responses to each of the consultation questions in the document, along with additional commentary, where relevant.

This submission has been co-developed with input, guidance and evidence from providers of early childhood developmental supports, and families of children on the autism spectrum. It has also been informed by extensive and ongoing consultation with families and service providers across Australia during the development of the Reimagine Australia Earl Childhood National Action Plan to 2030 (Reimagine Australia, 2020).

RA strongly recommends that this submission is read in conjunction with Early Childhood Intervention Australia (ECIA) National Guidelines for Best Practice in Early Childhood Intervention (Early Childhood Intervention Australia, 2016), and the Action Plan to 2030 (Reimagine Australia, 2020), which provides an in-depth and evidence-based analysis of the landscape of early childhood intervention in Australia, along with our plan to realise our vision for a future where every child has every possibility.

# A Note About Families

Reimagine Australia (RA) would like to acknowledge and highlight the uniqueness of every child and every family. The early years are important for all children and families, regardless of challenge, circumstance, or ability.

Supporting the whole child, and their whole family (which includes but is not limited to parents, carers, siblings and extended family members) is a critical element of ensuring that every child has every opportunity to live their best life.

The Autism CRC's report on non-pharmacological interventions for children on the autism spectrum (Whitehouse et al., 2020) highlights the importance of involving families in the provision of early childhood developmental supports.

In their 2008 report, the Australian Institute of Family Studies reported a range of impacts associated with caring for a person with a disability, including mental and physical health, employment limitations and financial hardship, to name a few (Edwards et al., 2008).

The central role of families in the lives of young children must be recognised, valued, and supported if optimal outcomes for children who are developmentally vulnerable are to be realised. RA encourages the reader to remember that every family is different, and that all members of all families require support.

> *"Life is a struggle but with support, I can do it."*
>
> \- *Mother of a child on the autism spectrum*

# A Note On Terminology

In line with the statement provided in the Autism CRC report, Reimagine Australia (RA) recognises that there is no one term that will be preferred by all people.

RA has adopted the 'child/ren on the autism spectrum' or 'child/ren on the spectrum' throughout this document, as this language places the child first.

We also acknowledge that many people prefer the terms 'autistic' or 'autistic person' to describe themselves. These terms reflect the view that being autistic is a core part of who a person is, and we support the right of every person to refer to themself in ways that are right for them.

# Consultation Questions

Reimagine Australia (RA) has consulted with parents and professionals with an interest in supporting children on the autism spectrum. Stakeholders who gave their input included:

- Parents of children on the autism spectrum who are accessing NDIS funded supports.
- Allied health and early childhood professionals from a range of disciplines, including those working:
  - In private practice or private businesses
  - In the non-government / not-for-profit sector
  - In the government sector
- Academics and research professionals from allied health and education backgrounds.
- Managers of early intervention services that work with children on the spectrum and their families.

Stakeholders who participated were from the ACT, New South Wales, South Australia, Western Australia, Queensland, Victoria and Tasmania. There was representation from metropolitan, regional and rural communities.

The initial consultation session was a group video conference held on Tuesday the 12th of April. There were 50 callers who joined the video call, with many callers joining in with a group of other people from their workplace who all contributed. Following this initial consultation, several individuals and organisations provided additional feedback by email, or booked an individual meeting to discuss their feedback. Several Australian and international academics also reached out to support the submission by providing access to their research about best practice for children who are on the autism spectrum and their families.

The first draft was made available for review between Thursday 22nd of April and Tuesday 27th of April. Feedback received during this initial review period was reviewed and incorporated into the second draft document which was made available for review between 4th of May and 10th of May. Additional feedback by email and through individual meetings with individuals and organisations was used to inform the final draft, which was presented to the Board of Reimagine Australia on Thursday 13th of May.

Stakeholder responses to each of the consultation questions are outlined below.

## 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

RA stakeholders expressed that they do not use the NDIS website, the NDIS operational guidelines or NDIS partner contacts as sources of information about choosing and accessing services for children on the autism spectrum. Stakeholders were not able to give opinions on the usefulness of documents such as the participant decision making guidelines, which have not been developed and therefore, cannot be reviewed.

RA stakeholders noted a perceived conflict of interest associated with the assertion that the NDIS could be an unbiased source of information on best practice for children on the autism spectrum. RA acknowledges that the NDIA has put in place a range of policies, procedures, checks and balances to remove perceived or actual conflict of interest, however our stakeholders did not feel that it was appropriate to have the NDIA providing advice or recommendations about best practice or appropriate interventions while also making decisions about the funded supports in participant plans.

There is a need for collaboration and consideration of intersectional service needs, that is, needs that a person on the spectrum has which are not directly associated with their diagnosis of autism.

RA suggests the establishment of an independent navigator service within a universal service system, that walks alongside families to access unbiased, evidence-based information from the very beginning. A family navigator service would need to be both credible, experienced, and unbiased. That is, an organisation that is neither a service provider, nor a funding body. This recommendation relates to *Priority Area 3: Seamless and Integrated* and *Priority Area 4: Responsive and Relational* in the Action Plan to 2030.

The independent navigator service would employ staff who are skilled, qualified and experienced in aspects of early childhood development, and have a thorough and unbiased understanding of the best available evidence across a range of areas. The navigator services would be embedded within local communities and therefore, well placed to recommend and link families with local mainstream services and supports in the first instance. The navigator service would function as a ‘key worker’ for families, particularly in their early days, taking on some of the responsibility for setting up a coordinated and collaborative team for each child and family.

RA stakeholders expressed their view that the role of the NDIA is to provide access to reasonable and necessary funded supports, not to determine which supports are best for a child and family. The agency may take the position that particular therapy approaches will not be funded under the scheme, but this does not necessarily mean that families don’t or won't choose these approaches, or that they don't or won't make a difference in the life of that child and family. The navigator service could help ensure that all families have the opportunity to fully understand the evidence base, so that they can make good decisions about what's right for their child and family.

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

Providers and professionals told RA that they were likely to consult the literature relating to interventions or services to develop their understanding of the intervention in order to provide parents with unbiased information. Providers access information through professional networks, peak bodies relating to their field of professional practice, government and local government directories, evidence based online resources. professionals access supervision and/or mentoring to develop their clinical practice and ensure that their practice is informed by the best available evidence at all times.

Parents told RA that they were likely to consult with other parents and with the people and organisations in their child's support team. Parents also often use the internet to search for information and to connect with online communities to inform their decisions, noting that research shows that while there are sources of reliable information online, much of the information available for parents online does not generally represent high quality health information (Grant et al., 2015).

Parents have identified that they need more support to understand the evidence base and use the evidence to make informed decisions. The challenge we face is finding ways to support parents and caregivers to appraise the quality of the information they are accessing (Di Pietro et al., 2012). Parents value the relationships they have with their service providers and would like to see a funding model that supports providers to do this more comprehensively. Refocusing the ECEI approach on collaborative teamwork, while recognising and funding activities that providers undertake between therapy sessions to support children and families, would help to ensure families are provided with timely, unbiased and evidence-based information that would help families make decisions (Grant et al., 2016).

RA would like to see an increased focus on empowering and resourcing caregivers with information, resources and choices, through the establishment of an easy to navigate pathway for families to access early childhood supports and information. RA has proposed the introduction of a family navigator service, building on and existing within a universal service system which would be the main point of contact for all families of children with developmental vulnerabilities from the very beginning.

RA suggests that the reader refer to the recommendations made in relation to *Priority Area 1: Empowered and Resourced* in the Action Plan to 2030, which highlights the need to establish easy to navigate pathways, and a no-wrong-door approach to universal service provision.

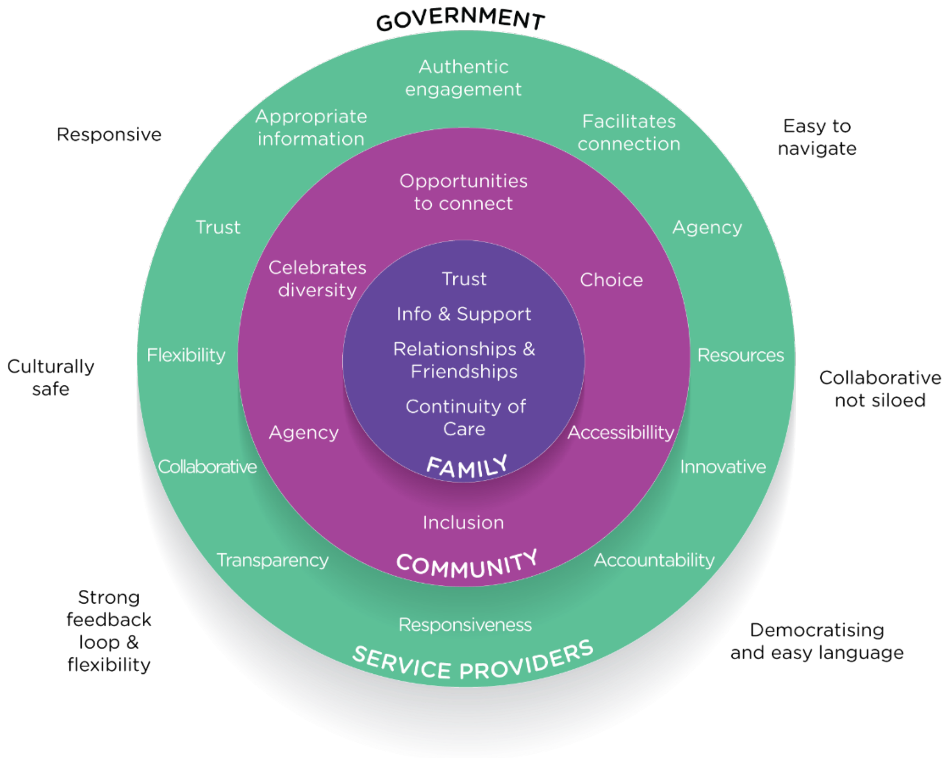
3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. How can we help families to find and connect with other supports outside of NDIS?

RA is concerned that the inclusion mandate in universal services has been compromised with the introduction of the NDIS and believes that the NDIS has inadvertently segregated specialised support from the universal service system.

The role of the child and family's planner in providing information, supports and links with mainstream supports must not be overlooked. There is room to improve the focus on holistic supports, including funded supports, at the planning level.

The RA Action Plan to 2030 consultations found that that the number of specialist supports involved in a child's life increase with the complexity of the child and family needs. We know that best practice for all children, and all children on the autism spectrum, involves collaboration. An unintended consequence of the introduction of the NDIS has been a significant swing towards individualised therapeutic supports, and away from holistic, collaborative, and integrated supports (including but not limited to individualised therapeutic supports).

*Image 1: Circles of Support*



All parts of the early childhood ecosystem require care and cultivation to ensure that they are ready, willing and able to support children who have developmental vulnerabilities. There need to be incentives for existing service providers to work collaboratively, which requires a review of the content and application of the NDIS price guide to better reflect contemporary approaches to best practice in the early years. This may assist families to recognise and value collaboration and inclusive supports when implementing their child's plan.

Holistic planning relies on the existence of a seamless and integrated early childhood development system that ensures there is ‘no wrong door’. RA would like to see the NDIA working in formalised partnership with early childhood providers in more effective ways. The reinvigoration and review of the provision of short terms supports to all children who have developmental vulnerabilities, including children on the spectrum, along with increased access to information, linkages and capacity building supports is also encouraged.

RA suggests that the reader refer to the recommendations made in relation to *Priority Area 1: Empowered and Resourced* in the Action Plan to 2030, which highlights the need to establish easy to navigate pathways, and a no-wrong-door approach to universal service provision.

## Reasonable and necessary

4. The consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum.

While RA stakeholders were broadly supportive of the sentiment behind the best practice principles proposed in the consultation paper, they were unsure of the purpose, audience, and intended use of the principles.

Further discussion of the principles uncovered a range of questions and concerns largely relating to the subjective and generalised nature of the statements. In many cases, stakeholders found the examples provided to illustrate the meaning of each principle were not useful and were a deviation from the point rather than an illustration of the point.

RA recommends that NDIS operational guidelines are underpinned by a strong outcomes framework for children and families, where the focus is firmly on understanding areas of need and matching appropriate supports to these areas.

Stakeholders gave specific feedback about each of the principles, and a summary of these comments is provided below:

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

This principle, read in isolation, is subjective and open to interpretation. It is difficult to measure a ‘good understanding’. While this principle is useful, it is not clearly worded, and will be difficult to apply consistently if the intention is to use these principles to make decisions.

RA stakeholders also noted that our understanding of autism has changed over the years, and coming to an agreement on what autism is, and what it isn’t, may make defining a ‘good understanding’ even more challenging. Depending on the intended use, purpose and audience of these principles, this principle may need additional description and qualification in line with the current evidence base.

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

RA agrees that the people who deliver the interventions should know the person well and respect their feelings and views. This principle is well aligned with the National Guidelines for Best Practice in Early Childhood Intervention (Early Childhood Intervention Australia, 2016).

RA would like to see a shift towards more holistic, family centred plans that recognise the key role that family and community play in supporting children to participate and be meaningfully included.

> *"ASD is a lifelong condition. My child needs support and help over their lifetime. And so do I."*
>
> *- Mother of a child on the autism spectrum*

Stakeholders questioned the wording of the following phrase in the description of this principle: *'many people delivering intervention require the requisite training and qualifications and should work very closely with the child and families as equal partners'.*

RA recommends that this statement is amended to highlight that *all* people delivering interventions should have the appropriate training required to deliver that intervention. This amendment speaks to the importance of collaborative teamwork practices where parents are guided and coached to be the primary agent of change in their child's life. Extending this idea, RA recommends further exploration of methods to facilitate transference of specialist knowledge from providers to caregivers and other members of the child's support team. This knowledge-sharing and capacity building is key considering the evidence that caregiver responsiveness and interaction style, along with involvement in provision of therapeutic intervention has a positive impact on child outcomes; these collaborative teamwork practices need to be funded appropriately if they are to be delivered effectively (Binns & Oram Cardy, 2019).

### The intervention is adapted to the needs of the person receiving it

RA supports the need for individualising therapeutic supports to suit the child and their family in the context of their broader ecosystem. RA stakeholders commented that this principle seems to be at odds with the proposed indicative levels of funded supports, which are discussed later in this submission.

### The intervention is based on a theory that is logical and scientifically plausible.

This principle, read in isolation, is subjective and open to interpretation. What may seem logical or plausible to one person may not seem so to the next person, and a uniform position on scientific theories, which are often adjusted and adapted may be difficult to agree on.

RA stakeholders expressed concern that this principle does not leave room for the development or piloting of innovative interventions that apply logic and scientific plausibility in new and different ways.

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

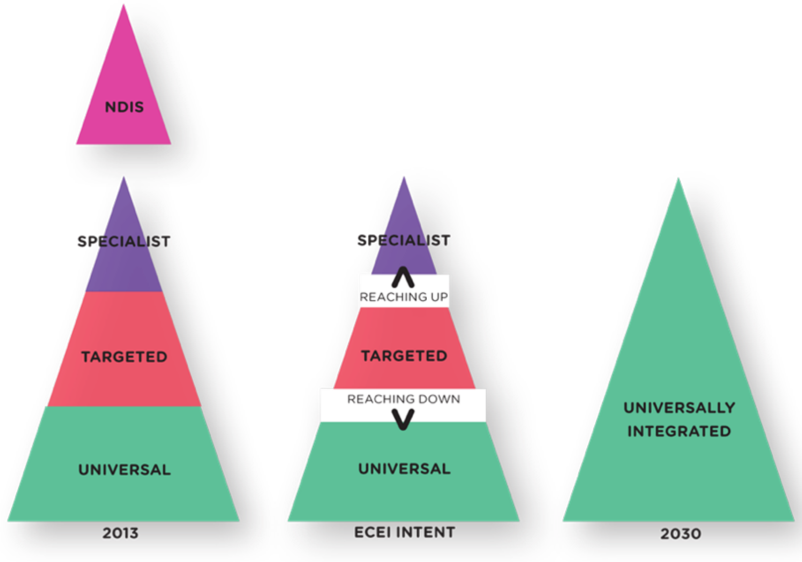
RA recognises that the NDIA advocates strongly for evidence informed best practice approaches, that work in the real world. However, there are limited incentives for organisations to deliver services in innovative, collaborative, and connected ways under the current individualised funding approach. It is important that funding, processes, and mechanisms are designed in ways that support the delivery of evidence informed practice which is derived from a range of evidence sources.

Additionally, both parents need a way to access and understand what the evidence says about interventions to make informed choices quickly and easily. Parents of children with developmental delays and disabilities often report significant levels of stress and mental ill health, which impacts on their capacity to find, unpack, and understand research (Edwards et al., 2008).

RA stakeholders highlighted that many families experience layers of vulnerability in addition to the risks that are associated with having a child with a developmental vulnerability or disability. The impact of other factors that are known to impact on child and family outcomes, such as exposure to domestic and family violence, lower levels of parental education and socio-economic disadvantage, must not be discounted and cannot be separated out from one another (Begum & Mamin, 2019; Delobel-Ayoub et al., 2015; Kelly et al., 2019; Mathew et al., 2019).

Shifting the pendulum back towards universal, seamless, and integrated service systems that collaborate to match services and supports with the needs of the child and family would help to drive quality and innovation across all service systems.

*Image 2: Towards the Future State*



RA recommends ongoing investment in quality research, data collection and monitoring systems and outcomes to build an innovative and adaptable early childhood sector. This recommendation relates to Priority Area 6: Outcomes and Innovation from the Action Plan to 2030, which highlights the need for meaningful data on developmental and participatory outcomes for children and families that is used to drive poly change, research, and innovation in Australia.

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

While RA stakeholders are strongly supportive of the need for developmental supports to have a solid evidence base, they also noted that there are many examples where interventions not specifically designed for use with people on the autism spectrum are, nonetheless, effective for certain people with certain needs. Recalling that nearly 3/4 of children on the autism spectrum have an additional developmental, medical or psychiatric condition (Raising Children Network, n.d.), interventions need to be effective for a range of developmental vulnerabilities. This statement negates the critical focus on each child and family achieving their individual goals, effectively using each child as their own control, against which progress is measured.

> *"Co-occurring conditions can appear at any time during a child's development. Some might not appear until later in adolescence or adulthood. Sometimes these conditions have symptoms that affect how well autism therapies and supports work. So it's important to identify and diagnose the conditions and treat them separately."*
>
> *Raising Children Network*

**The intervention supports mainstream and community participation.**

RA strongly agrees that early childhood developmental supports should facilitate and enable mainstream and community participation. However, RA is concerned that the inclusion mandate in universal services has been compromised with the introduction of the NDIS.

The structure and implementation of the NDIS appears to have exacerbated a range of challenges facing families and service providers as informal supports have eroded and silos of funded supports have been strengthened (The Scope-University of Melbourne Partnership, 2020). There is an urgent need to focus on re-balancing the early childhood ecosystem, with a focus on re-building the capacity of the inner 'circles of support' (see Image 1) that are so critical to outcomes for children with developmental delays or disabilities.

There appears to be a mismatch between the way that supports are funded through the NDIS (generally therapeutic line items), and the intended or possible use of these funded supports. Funding allocations are typically determined by participants in collaboration with NDIS Planners, many of whom have little experience in the disability services sector, and in autism in particular. Participants and providers report that there is very little consultation with, or consideration of, recommendations made by experienced practitioners when making access or planning decisions (Malbon et al., 2018; Mcdonald et al., 2016).

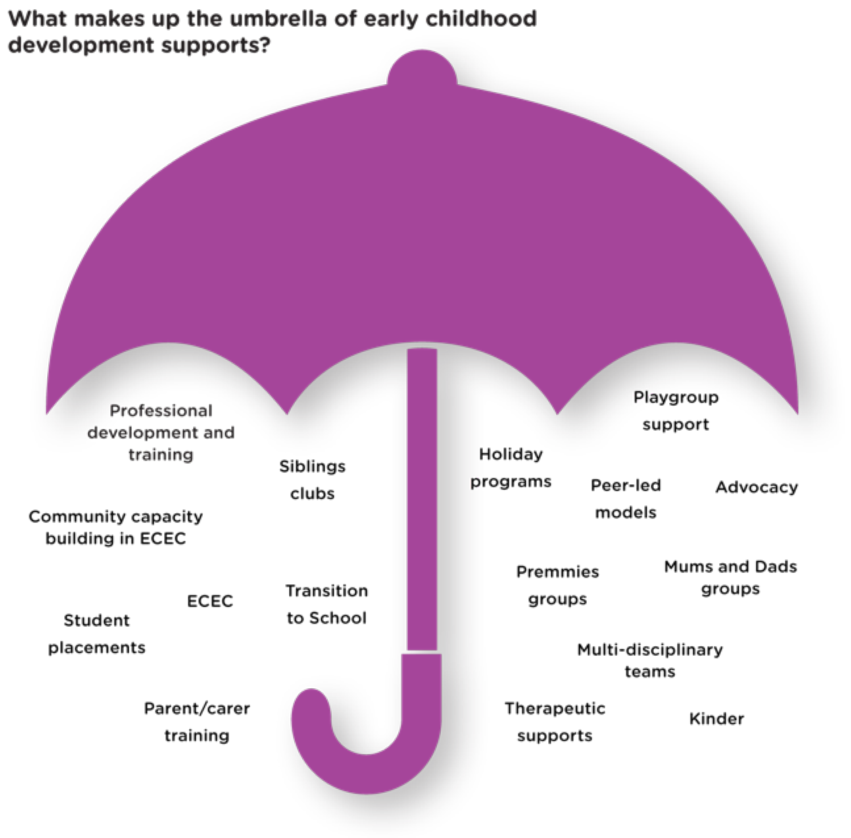
There appears to be a tendency to prioritise diagnostic classification over functional assessments when allocating supports for children on the spectrum (The Scope-University of Melbourne Partnership, 2020), and RA stakeholders think the proposed funding model will not address this disparity.

Standardising levels of funded supports, albeit indicatively, will continue to result in practitioners being driven to make decisions about treatment dosage and intensity based on the available funding, rather than clinical best practice or need (The Scope-University of Melbourne Partnership, 2020).

RA is recommending a recalibration of the early childhood ecosystem, which promotes the rights of the child, collaborative teamwork, and incentives for service providers to focus on parent coaching, capacity building and meaningful participation.

RA suggests that the reader refer to the recommendations made in relation to *Priority Area 2: Meaningful Participation* in the Action Plan to 2030, which highlights the importance of complementing individualised funding with other evidence-based supports to build a fully inclusive, holistic, well-resourced, and innovative early childhood support system.

*Image 3: Umbrella of Supports*



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. Is there anything you would like to add?

While RA stakeholders were broadly supportive of the standards proposed, again they were unsure of the purpose, audience, and intended use of the standards. Stakeholders expressed concern about generalised wording used in the standards that was open to interpretation and could therefore build inequality into the system.

With some revisions, stakeholders felt that these standards could be a useful guide to help families make informed decisions about the services and interventions they choose for their children. Currently, parents are not well supported to make informed and evidence-based decisions for their child, and want tailored, individualised support to help them do this (Grant et al., 2016).

Stakeholders gave specific feedback about each of the standards, and a summary of these comments is provided below:

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

RA agrees that professionals providing services to children and families need to be appropriately skilled and experienced. However, RA stakeholders questioned the mechanism through, and standards that would evaluate skills and experience. It would be useful to provide resources that support parents to ask questions that help them understand the skills and experience of their team, as well as how the team accesses professional support and supervision.

Retaining allied health professionals, and particularly, those with appropriate knowledge and skills to meet the needs of children on the spectrum, continues to be a challenge (Malbon et al., 2018). In 2018, National Disability Services reported that allied health practitioners were the most difficult staff to attract and retain in the disability service sector, particularly in regional and remote areas (National Disability Services, 2018) and less than half (43%) of disability service providers indicated that they expect to be able to meet future demand for services (National Disability Services, 2017). These trends are echoed in the 2020 State of the Disability Sector Report 2020 (National Disability Services, 2020). Early childhood educators are another group of professionals who are often overlooked as part of the early childhood ecosystem. Hays identifies Centre Directors, Early Childhood Teachers, and Diploma Qualified OOSH Coordinators as ‘in demand’ skill areas (2021).

RA would like to see an accessible, affordable, and sustainable accreditation process, available to all early childhood professionals and providers working with young children in the early childhood space that could be used to drive innovation and best practice service delivery. Co-design with discipline specific peak and regulatory bodies could result in a central database of services and supports that families could use to search for, contact and engage with services providers.

RA agrees that individualised supports need to be supported by the best available evidence, demonstrate Autistic cultural competency, and be delivered by experienced practitioners however the problem of integrating research evidence into practice remains an ongoing challenge (Paynter et al., 2017; Paynter & Keen, 2015).

Stakeholders commented that recognition of qualifications and experience in professional disciplines is currently managed through professional bodies and associations. They suggested that additional accreditation processes would be best focused on non-therapeutic skills and centred around the adoption of best practice guidelines such as the ECIA National Best Practice Guidelines. RA would welcome the opportunity to collaborate with the NDIS Quality and Safeguards Commission on the ensuring that the NDIS Workforce Capability Framework includes and addresses best practice principles by early childhood specialist support providers.

The overall issue that was expressed by RA stakeholders in response to this question related to the current workforce issues in the early childhood sector. In many areas, there is a high demand for providers, and choosing not to access support from a particular provider may not be an option. There is a thin market issue at play, and it is common for families to wait many months to access services and supports, and the group were wary of creating any additional barriers for families by requiring providers to meet additional standards outside of those that already exist.

Research has indicated that parents make decisions about which providers to access based on cost, location and availability rather than on the evidence base or on the best fit for their child and family (Grant et al., 2016).

> *"Many families nationally are encountering significant waitlists and as a result, the choice for families is less about an informed decision relating to quality, best practice evidence-based therapy, and more about accessing any therapy to support their child and family."*
>
> *- RA Stakeholder*

RA recommends the development of a comprehensive workforce strategy that addresses capability, quality and workforce supply issues. This recommendation relates to *Priority Area 5: Capabilities and Quality* in the Action Plan to 2030, which discusses the need for a skilled, collaborative and diverse workforce that delivers a range of evidence-based developmental supports for children and families.

### The people delivering the intervention follow established guidance

RA stakeholders agree with this principle but also noted that there are not always clear guidelines on implementation of evidence-based practice in particular contexts. In such situations, qualified and experienced clinicians should work to balance evidence-based practice, with practice-based evidence to deliver supports that are tailored to the strengths and support needs of the child and family.

### The intervention provides significant and lasting benefits

RA agrees that interventions should provide significant and lasting benefits, however, the threshold for what is 'significant' and what is 'lasting' is difficult to determine. The impact of maturation, changes in support needs and impact of additional developmental vulnerabilities, among other factors, can impact on the benefits that a child and family experience from a particular intervention.

RA stakeholders emphasised the importance of focusing on outcomes at the level of the child and their family. They also identified the need to use appropriate outcome measures, which should be individualised, to inform judgements of efficacy and benefit over the long term. Finally, RA stakeholders highlighted the evidence that demonstrates that 'long lasting' benefits come from a focus on collaborative, and capacity building practices which are difficult to measure, but critical to the outcomes of each child and family.

### The intervention is carefully monitored and reviewed on a regular basis

RA stakeholders agree that regular monitoring of progress against goals, and the use of appropriate outcome measures to inform judgements around efficacy and goal attainment are required. NDIS goals are often worded broadly and in general terms, and so, progress against these goals can be difficult to measure and report on.

RA suggests the introduction of Meaningful Practice Plans (MPPs) as described in the Action Plan to 2030, which build on the current provider report forms, but have a greater focus on promoting partnerships with family, community and other service systems (Reimagine Australia, 2020). MPPs could also be used to encourage providers to describe specific goals, and areas of focus that align with each broad NDIS goal. Collaboration between service providers could be encouraged using a secure online reporting platform where all providers can input their clinical or developmental goals, demonstrate how they relate to NDIS goals, and describe the types of services and supports they have used and what outcomes have been achieved.

RA also suggests that the NDIA considers the addition of family goals in addition to participant goals within NDIS plans. This is another way that providers can be encouraged to consider and address needs and goals in holistic and family centred ways.

### The intervention does not cause significant physical or emotional harm

This statement is challenging in its current form as it implies that if an intervention causes physical or emotional harm that is less than significant, that it might be acceptable. Any intervention that physically harms, restrains or restricts children is not acceptable.

### The benefits outweigh any costs (including risks)

RA agrees with this statement if the word 'cost' is interpreted as 'risk of harm' rather than monetary cost. Any intervention that causes harm, or is likely to cause harm, is not acceptable. The intention behind this standard appears to be that developmental supports should be beneficial and should not cause harm. This standard could be combined with the previous standard and clarified.

**The intervention is good value for money and time invested**

RA stakeholders agreed that therapeutic supports should represent good value for money and time invested but questioned how value for money is measured. The primary aim of providing early developmental supports is to reduce or eliminate the impact of developmental vulnerabilities over a lifetime, not a one-year planning cycle. RA stakeholders expressed concern about the proposed pathway for children on the autism spectrum is into, through and back out of the NDIS, when what we know is that autism creates life-long challenges that change (increasing or decreasing) over the course of a lifetime.

6. “Reasonable and necessary” is a term from the NDIS 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”?

RA stakeholders did not think that the case studies helped to clarify the term ‘reasonable and necessary’; they felt that the case studies were unclear, confusing, and often did not appear to explain the concept that they were intended to illustrate.

RA stakeholders commented that in some cases, the case study did not make it clear whether the decision that was made represented ‘reasonable and necessary’ or ‘unreasonable and unnecessary’. It was suggested that if case studies are used, they should be co-designed with parents and providers, and reflect a range of scenarios where a clear decision is made and explained.

7. Do you have any other feedback about how we explain “reasonable and necessary?”

RA is aware that there continue to be significant differences between plans for children who could be considered to present with a similar level of need. RA stakeholders would like to see an increased level of transparency with regards to reasonable and necessary decision making, and a quicker, easier mechanism through which families can appeal or review allocated supports in their plan.

8. Table 2 (0-6 years) and Table 3 (7-12 years) are examples of how we might explain indicative levels of funded support for children on the autism spectrum. Do these table/s clearly explain the indicative levels of funded supports?

RA stakeholders strongly disagreed with the proposal to adopt indicative levels of funded supports for children on the spectrum as described in Tables 2 and 3 of the consultation paper. Broadly speaking, the approach appears to be based on a number of incorrect assumptions, and on a simplified interpretation of the evidence base presented in the Autism CRC research review.

9. Do you have any other feedback about how we explain the indicative levels of funded supports?

A summary of the concerns raised by RA stakeholders is presented below:

a. While RA understands that the NDIS is an insurance scheme that aims to provide supports to people that will reduce their need for supports in the future, it is not possible to standardise or forecast if, when, how much or how quickly the needs of a participant will change. The paper states that *'we would expect to see a reduction in funding as a participant's capacity increases'* and while this statement is an ideal outcome, there will be cases where a participant's needs increase, or fluctuate as their goals and aspirations change over their lifetime.

   The paper describes a reduction in funded supports at key transition periods as a reflection of the increased role that other service systems (i.e. education) have to play in the lives of children on the spectrum. RA stakeholders expressed that transition periods are moments where increased supports are required by most children on the spectrum, rather than less. Routine and predictability can be protective factors against mental ill-health for children on the spectrum. Moments when routines and schedules are interrupted, such as times of transition can lead to additional stress, anxiety and depression, that can reduce the person's functional capacity (Hedley et al., 2017; Leekam et al., 2011; Uljarević et al., 2020; Uljarević et al., 2017).

   RA believes that all service systems under the umbrella of universal supports need to play their part in supporting children and families, however capacity building within universal supports is not a one-off task. Staff turnover and system changes require ongoing capacity building to ensure children are welcomed and supported in universal service systems. As children grow and change, they move into new and different environments, one of which is school. Each time a child encounters a new environment, there are opportunities and imperatives to build capacity to support that child.

   There is no 'one size fits all' approach to service delivery, and it is unsurprising that there is variation across budgets, and across observed budget reductions when children start school. Every child is different and comes with a unique set of strengths and challenges which need to be considered on their merits on an individual basis. Collective assumptions about what children on the spectrum will do, be and benefit from has the potential to cause harm.

b. The levels of funding described in the tables are indicative, however RA stakeholders expressed significant concern that the indicative levels may inadvertently end up being applied as absolutes rather than a starting point for an individualised approach. Providers and parents report frustration around their experiences of providing evidence of functional impact or need and having the evidence they present put aside or ignored during their planning process.

   The descriptions of 'this may look like a child with…' in the tables do not reflect realistic or useful descriptions of areas of functional need. For example, even when describing 'high' functional impacts, there is a bias towards describing the skills of a verbal child on the spectrum who has communication limitations; the example being that a child with high needs can *'request basic needs, cannot take more than one turn in conversation and can follow one step instructions.* In reality, many children with autism are non-verbal or minimally verbal (Lund et al., 2021), many cannot take any turns in conversation, and these realities are not reflected anywhere in the descriptions provided. Some of the descriptions are quite stereotypical and make sweeping generalisations about what autism looks like that are unhelpful and not accurate.

c. The proposed model focuses on building the capacity of the child, however high-quality early childhood supports have a much broader focus than this. Children exist within families and communities, and each child's social context along with the capacity of the family, and of the child's parents or caregivers is critical when it comes to ensuring great outcomes for children on the spectrum.

   Families of children on the spectrum report feeling overwhelmed and exhausted by the amount of additional effort that it takes for them to care for their child. Their support needs change as the needs of the child change and supporting families through capacity building throughout their child's life (not just at the beginning) is an imperative. While the provision of longer term supports comes with a higher up-front cost to the scheme, the impact of not providing these supports is likely to be much more costly over a lifetime.

d. Many parents are operating from a mindset where funding is something that needs to be fought for. There is a sense that funding is scarce and difficult to access, and so, once funding has been secured, there is an imperative to maintain or increase the level of funded supports that the child has access to. Providers are often asked to down-play a child's achievements for fear that their funded supports will be reduced. RA would like to see a re-setting of the early childhood system that focuses on building all areas of the early childhood ecosystem, the anticipated result is that there would be a reduced sense of 'scarcity' because families know that they will be able to access the supports and services that they need when they need them.

e. RA stakeholders were cautious about statements relating to the ability of parents to find or negotiate lower cost supports. Many parents continue to believe that more supports are better, whereas RA believes that the amount of support is less important than the way in which those supports are delivered. RA does not agree with the establishment of models of funding that encourage undercutting and cost saving in the service market; quality services don't need to cost more, but they also generally don't cost less. Families need to be supported to think critically about the services they access, but this should be driven by quality and outcomes rather than by cost, in the first instance.

f. RA stakeholder provided examples of where a child receives a diagnosis of autism at an older age; in these situations, a child who is 7 or 8 when they are diagnosed would immediately be considered against levels of indicative funding for older children, when realistically, their needs are likely to be higher than this immediately following diagnosis. Issues with delayed access to diagnosis, and barriers to accessing early childhood developmental supports (e.g., wait lists, geographical location etc.) are of concern when assumptions are made that age is a key determinant of the level of the support a person needs.

g. The paper states that *'a small number of children who require some further consideration due to other factors, for example where they have additional disabilities or significant behaviours of concern'*. RA would like to highlight that a large proportion of people on the autism spectrum have other disabilities, and around 2/3 people on the spectrum experience profound or severe disability (Australian Bureau of Statistics, 2020). Children on the spectrum often present with complex and nuanced needs. It is not correct to assume that only a small number of children will require further consideration of their support needs.

h. RA stakeholders questioned the methods that will be used to measure functional impact and to determine the level of needs. Holistic assessment should be completed by people who know the child and family. In the context of the recent pause on the rollout of independent assessments, RA would like to call out the critical importance of parents and professionals working collaboratively to make informed appraisals of the functional needs of the child and the services and supports that are required.

i. The paper discusses scenarios where children who may receive a diagnosis of autism could be offered short term supports for up to 12 months with an early childhood partner before a decision is made about whether to test eligibility for the scheme. A range of serious concerns about this were raised regarding the impact of denying a child access to services that they need.

   Firstly, there is significant variation in the availability of short term supports provided by early childhood partners. Some regions report that these supports are available, while other regions do not have any access to short term supports. Short term supports have an important place in providing children with responsive and immediate supports but should not be used as a tactic delay or avoid entry to the scheme.

   Providing short term supports only, in the hope that children on the spectrum will not need to enter the scheme is not an appropriate strategy. Children need to be able to access early, appropriate and often intensive interventions to develop foundational skills in early childhood. Any delay in accessing the right supports places children and families at risk for increased disability across their lifetime.

j. Separating out children on the autism spectrum from the larger group of children with developmental vulnerabilities could be perceived as discriminatory. Children with a diagnosis of autism will be considered against these tables describing reasonable and necessary standards for children on the autism spectrum, rather than against reasonable and necessary supports for children in general, which creates inequality and bias in the system. Remembering that approximately ¾ of children on the spectrum have additional diagnoses, the indicative levels of funded supports are out of touch before they have been considered.

k. Blanket statements such as ‘up to one school visit’ are limiting. Providers and parents need to be able to use their funding flexibly and in a responsive manner. There are situations where more than one visit to an educational setting is required. Placing additional rules around how much of each service a child may access, when, and where, is unhelpful and reduces the child and family’s choice and control.

l. Long waitlists to access diagnostic and therapeutic services in many areas can result in children missing out on valuable early childhood supports. Under this proposed funding structure, children who are diagnosed when they are at (or close to) school age, may receive less support because of their age. The impact of parental responses at diagnosis, and capacity to engage with supports must also be considered.

m. The suggestion that through the provision of early childhood supports, children with autism could completely exit the scheme is unhelpful. Autism is a lifelong condition. While some people on the spectrum do not identify as having a disability, or experience functional limitations in their daily life, the majority do experience significant barriers across all areas of life. RA calls for a refocusing on ensurance and assurance, rather than solely on insurance. While the up-front costs may be higher, the cost of not providing supports will inevitably be greater over the course of a lifetime.

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?

As discussed above, there are many and varied examples of times when families or carers need extra supports. RA is calling for a seamless, integrated, collaborative and coordinated approach to the provision of early childhood developmental supports for all children, including children on the spectrum.

RA refers the reader to the Reimagine Action Plan to 2030 and to Getting Back to the Future, a recent submission from RA in response to the NDIS consultation paper relating to how the NDIA works for young children for commentary on a range of considerations and recommendations that have been proposed to improve the provision of early childhood supports in Australia.

## 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 of the NDIS consultation paper 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 the questions in Section 8.2 of the consultation paper helpful for parents and carers when selecting providers?

RA stakeholders felt that while the list of questions is not un-helpful, they are very general and may not adequately guide parents towards selecting high quality providers. Parents often have a poor understanding of what the evidence means, and often make decisions based on anecdotal reports of an intervention’s perceived effectiveness (Grant et al., 2016).

RA suggests the development of a ‘looks like / doesn’t look like’ document that explains what quality early childhood developmental supports are about. Best practice is a continuum, and it is always changing. It is important that parents understand the rationale behind asking each of these questions, and what ‘good’ looks like. A system wide approach to improving understanding of best practice in early childhood intervention that addresses knowledge and capability gaps across all parts of the early childhood ecosystem is recommended.

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?

RA refers the reader back to the National Guidelines for Best Practice in Early Childhood Intervention which sets out a range of best practice principles to guide delivery of holistic and family centred services (Early Childhood Intervention Australia, 2016). We also refer to the Action Plan to 2030 for additional insights into the barriers that families are experiencing and the recommended actions to reduce and remove these barriers by 2030 (Reimagine Australia, 2020).

RA would welcome the opportunity to work with the NDIA and collaborate with mainstream information sources to develop an easy to use, accessible, and evidence-informed decision-making tool to support parents and providers to access the best available evidence to inform decision making. It is critical that these types of resources are co-designed with the people who will use them to ensure that they are fit for purpose, and that they are regularly reviewed and updated to ensure they are always reflective of the best available evidence.

## Conflicts of interest

13. 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?

RA agrees that the provision of high quality, timely, and unbiased information is beneficial to children and their families. We believe that caregivers must be empowered with information, resources, and choice to support the development and wellbeing of their child and family.

The NDIA plays an important role in helping families understand what best practice looks like, and in providing families with information to assist them to make informed choices about the supports they access. The challenge at hand is not to interpret the research for parents or to prescribe what should be provided to children on the spectrum, but to present the research in ways that make it easy to approach and understand so parents can make their own decisions. The NDIA can support families and carers to make decisions about what is in the best interest of their child and family by continuing to support research such as the Autism CRC paper, and by working with parents and providers to understand their needs.

An easy way to search for information on programs, services, and service providers that is up to date, consistent and easy to navigate would help families to understand all their options, funded and unfunded. This resource should include a range of paid and unpaid supports, specialist supports and mainstream supports, ILC grant programs and how to access them etc. This tool could be used by an ECEI navigator, service providers, and families to support conversations and decisions about services and supports. The information provided needs to be in accessible language, without jargon. It needs to contain enough information to clearly explain the key ideas, it should be available in a range of languages, be sortable and filterable, and present all the options. Building on the resources available on the Raising Children website would be a useful place to begin.

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