

**Every Child Thrives: working with
young children, families and
community to support potential and
participation**

**Early Childhood Early Intervention
(ECEI) Implementation Reset**

**Response to Project
Consultation Report**

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1. Introduction

In May 2020, the National Disability Insurance Agency (the Agency) launched a range of reviews and consultation as a process of continuous improvement to the National Disability Insurance Scheme (the Scheme) and to address challenges and recommendations from the Tune Review.

This included review and consultation of supports for young people and families through the Early Childhood Early Intervention (ECEI) Approach. The objective of the review was to:

- Improve outcomes for young children and their families/carers;
- Enable the right children receive the right support at the right time, and
- Develop short and long-term solutions for identified pain points, challenges, and gaps.

Since 2018, The Benevolent Society has been the NDIS Early Childhood (EC) Partner in the Community (PITC) in ECEI for the Brisbane, Beenleigh, Caboolture and Strathpine regions. In this time we have had the privilege of providing parents with the knowledge, skills and support to enhance their child's development and ability to participate actively in their community. This has entailed facilitating a range of support pathways, including: connecting families with community support options, offering short-term intervention supports, and facilitating access to funded supports through the NDIS.

The Benevolent Society can provide a unique perspective on the proposed changes. As an NDIA partner, we have acquired insight into the journey of families as they engage with the ECEI and NDIS. Our network of Early Year Centres supports families with young children on a daily basis, including early intervention and support to navigate ECEI processes for families of children with developmental delay or disability. We have extensive experience across child support and protection systems and, in NSW, as a service provider in disability services. We have drawn on this experience to prepare this response and have consulted with many across our organisation, including

- ECEI Manager and Team Members;
- Director of Child, Youth & Family;
- Project and Implementation Lead, Child and Family Queensland;
- Director, Practice and Impact Management and team;
- Executive Director;
- Principal Advisor Indigenous Development;
- Disability Services Directors (NSW and SA); and
- Campaign Director, Every Child.

2. Overview/Summary

The Benevolent Society have welcomed the opportunity to be involved in the consultations through participation in the EC Partner Reference Groups and are generally supportive of the proposed changes.

Our experience as an EC Partner in the early implementation phase of ECEI strongly aligns to that described in the Project Consultation Report. The early focus of implementation was, necessarily, on

the transition of children already receiving state supports into the Scheme. From this time and, in accordance with the KPIs set by the NDIA, our team have prioritised working with families to determine pathways, develop plans and support full access to the Scheme with limited (if any) capacity to undertake the broader Partner functions such as connection and access to mainstream supports and early intervention.

While the continuation of support is important, key elements of the service were unable to be undertaken within the available resources. The impacts of this have been felt at all levels of the system:

- Children: many have missed out on the critical early intervention required to support their optimal and meaningful participation in family, community and society.
- Families: opportunities to implement best practice strategies, including to build the capacity of significant others in the child's life, have been compromised.
- Services: reduced capacity to develop partnerships and collaborate with services resulting in an increasingly siloed service system and in some cases, a shift away from inclusive practices in mainstream services.
- Communities: limited capacity to reach out into communities means that many children and families who are experiencing disadvantage are not receiving the supports they need.

This represented a significant shift away from 'best practice' in early childhood intervention recognized across the sector.

“We haven't been able to go above and beyond – to reach out to families, to services, to the broader community. It has jeopardized the fundamental premises of the Scheme”

Service delivery and outcomes for families have been further impacted by difficulties recruiting and retaining staff. Our initial recruitment drive attracted qualified team members who were motivated by the opportunity to work in the emerging NDIS environment with its potential to deliver best practice intervention and unprecedented outcomes for young children and their families. The subsequent focus on identifying and planning for participants entering the scheme has seen high turnover and impeded ongoing recruitment. The NDIA pricing is making private practice a more attractive prospect for Allied Health practitioners. The EC providers cannot offer a complete remuneration.

We support the Agency's desire to undertake a complete 'reset' of the ECEI Approach. It is our view that the early years of implementation have had a significant impact on the perceptions of the EC Approach by families and the community. For many people, engaging with ECEI has come to mean securing a plan and ongoing access to the NDIS and private providers, rather than focusing on meaningful goals and outcomes for children and families.

To change these perceptions requires more than 'tinkering' – it requires a 'reset', that takes forward the elements of ECEI that were working, and that seeks to reposition the EC Approach in an early childhood, evidence based, best practice intervention context. This is a culture change for all stakeholders – children and families; communities; providers; mainstream services; partner organisations; and the Agency to build a shared understanding of what is required for an effective early childhood approach. It must be internationally consistent, supported by a strong evidence base and include shared and mandated common standards.

“We need to go back to what we know is best practice and mandate shared standards if we are ever to regain what we lost in the early implementation – in terms of both the intention and the reputation of the scheme.”

Importantly, through the reset, the EC Approach must maintain a commitment to ensuring that young children and their families have access to the full range of supports necessary to improve outcomes including full access to the Scheme, as necessary.

The role of the Early Childhood (EC) Partner

The proposed reset significantly expands and increases the role of the EC Partner and, as such, it is reassuring that the recommendations acknowledge that the capacity of the EC Partners must be increased to deliver the enhancements described. The reset represents an alignment to best practice in early intervention and a shift to the role that The Benevolent Society has always been eager to play. We see that these changes can provide the opportunity for EC Partners to be leaders in the provision of best practice early childhood services to support children and families to be the best they can be. In particular, we look forward to implementing the following:

- Undertake Independent Assessments for young children (Rec 9)
- Increased capacity to connect families and young children to support networks and services through promotion of peer support networks (Rec 11)
- Increased capacity to deliver short term early intervention (Rec 12)
- Increased age range from up to 7 to up to 9 years old (Rec 14)
- Increased capacity and flexibility to tailor support and more quickly connect families to support through increased hours of ‘implementation support’ (Rec 16)
- Empower EC partners to provide advice on best practice and recommend providers (Rec 19)

In addition, the Benevolent Society would also like to see a renewed role in working with state and territory services such as health and education (Rec 5) and to be the leader in their region for early intervention.

Truly undertaking the role of EC Partner under the new EC Approach will require significant changes in funding and contract deliverables. While the consultation process and report have indicated the expectation of financial and productivity savings across the new EC Approach, the increased role for EC Partners, will require a significant increase in resourcing to truly deliver best practice.

Workforce challenges continue to be a risk to successful implementation of the NDIS, and this is also true in ECEI. Increased and changed roles for EC Partners will require a workforce which is greater in number and specialisation. The employment of allied health practitioners for independent assessments and to guide short term early intervention is necessary to service quality but carries the risk of further exacerbating skills and provider shortages across the sector. Further investment is required in workforce planning and development particularly at the local level, where place-based workforce strategies provide opportunity for collaboration and support across providers.

The need for a systemic response

Critically, the Benevolent Society sees that the NDIS sits in a broader context of family, community and system supports that are required to work together to successfully achieve outcomes for young children. Therefore, it is critical that any changes to the EC Approach respect this broader context and

seek to integrate early intervention supports within family and community systems. Families of young children enter a confusing and sometimes confronting system when their child is diagnosed – they require support to navigate systems and to build their capacity to select and participate in quality intervention with their child. It is also critical that mainstream services are able to effectively support where needed and are connected with the NDIS, particularly across state and federal divides.

First Nations response

A clear focus on working effectively with First Nations families and children must be developed and articulated. This must include a clear alignment with the Closing the Gap 2.0 outcome “*Aboriginal and Torres Strait Islander children thrive in their early years*” and support the achievement of the target of increasing the proportion of Aboriginal and Torres Strait Islander children assessed as developmentally on track in all five domains of the Australia Early Development Census (AEDC) to 55 per cent.

In line with the approach taken by the Closing the Gap agreement, this must be developed in partnership with Aboriginal and Torres Strait Islander people including shared decision making.

In Aboriginal and Torres Strait Islander communities, solutions must be developed and owned by the community and all efforts made for delivery to occur through community-controlled organisations. This is more than the “engage in consultation” that is referenced in Project Consultation Report (p 80). Support in these communities should follow the approach taken in the Closing the Gap partnership which identifies the following Priority Reform Areas:

- formal agreements and shared decision making;
- building the community-controlled sector;
- transforming government organisations; and
- shared access to data and information at a regional level.

The identification of the disability sector as one of the first four sectors to be supported through “Sector Strengthening Plans”, provides a significant opportunity to actively build the capacity of the community-controlled sector to effectively deliver disability services, including early childhood services.

3. Response

This section outlines our response to the Project Consultation Report. Predominantly this follows the consultation questions including (where applicable) reference to applicable recommendations. However, there are a number of important recommendations that are not clearly picked up in the consultation questions. Predominantly these fall under the broad “planning and implementation’ heading. A response to the individual recommendations has been provided in Appendix 1.

3.1. Planning and Implementation

Clarifying the interpretation of developmental delay

The desire to clarify the interpretation of developmental delay to provide certainty and reduce inconsistency is supported. In our experience, the current criteria are subjective and open to interpretation. However, the term has been in use in the broader health, community, and education

sectors for some time. It will be important that any clarification does not diverge from common usage and understanding as this risks creating more uncertainty and confusion.

The Benevolent Society understands the Agency is considering narrowing the definition of developmental delay and introducing a new term. The proposed new definition separates children who meet the requirements of developmental delay according to the legislation for access to the scheme, and those more suitable for short term interventions where the legislative definition is not met. Given the widespread usage of 'developmental delay' by a range of service providers, this risks confusing parents and creating an adversarial relationship between families and EC Partners/the Agency, whereby families may feel that EC partners are downplaying the impact of the delay in order to direct the family down a STEI pathway.

The Benevolent Society strongly recommends that the Agency undertake further consultation before finalising any changes. It will be important to consider how this change is communicated to families and communities, including agencies and practitioners who refer to the EC Approach. EC Partners will require resources to ensure transparency around decision-making and to align family and community expectations with any changes to eligibility criteria.

VIGNETTE: Confusion regarding the definition of developmental delay

A family is concerned about the progress of their child against a number of developmental milestones. They visit a paediatrician who diagnoses delays in a number of developmental domains and refers them to the local EC Partner. Upon assessment, the EC Partner determines that the child does not meet the criteria for developmental delay under the legislation and is therefore ineligible for a funded plan through the NDIS. As a result, the family is confused about the diagnosis; they feel uncertain about the support available; the paediatrician challenges the EC Partner's decision which undermines their diagnosis.

Introducing 'capacity building support in natural settings'

Best practice in early childhood intervention clearly articulates that effective supports are best delivered in a 'natural setting', meaning, in an environment where participation in activities occurs naturally, and is familiar to the child (as opposed to a clinical environment). Under the market model of the NDIS, one of the key levers to shape practitioners' behaviour is to incentivise action through pricing. Inclusion of a new line item for capacity building in a natural setting is therefore a positive step, but we feel this should go further. Steps should be taken to ensure that delivery in natural settings is the default and preferred option for all providers unless there are legitimate arguments for clinical delivery due to professional or situational reasons.

Success of this recommendation will depend on the level of pricing, and the inclusion of funding for travel time for the service provider. It will also be critical that the term natural settings is clearly defined, or a more 'plain English' term is adopted for communication with families.

There also needs to be further preparatory work done with ECEC providers and the state education system alongside ECEI to support better service system integration and consistency of practice. Currently there are many barriers for families and therapists to be able to access mainstream systems (noted natural settings) and pressure on ECEI coordinators to include in-home supports in a plan as access to these 'natural settings' is often refused.

Definition of 'reasonable and necessary' for decisions around support for children on the Autism Spectrum

As the EC Partner, the Benevolent Society has firsthand experience working with families and providers with intensive supports for children with Autism. The Benevolent Society agrees that this is a space that has not been clearly defined for families and providers. It creates a sense of inequity for families where they may have a child displaying the same level of functional impact of their disability but have decided not to enrol their child in an intensive program for children with ASD. It appears children in intensive programs tend to have plans agreed with more funding than those not enrolled. A transparent approach needs to be provided for families and service providers that clearly identifies the place of intensive supports for children on the Autism spectrum and in what circumstances these may be approved. Feedback from many families is that this feels like 'secret NDIA business' and that if they don't ask about intensive supports, they will never receive them.

We agree that it will be important to rely on the evidence available on what best practice in this space is while continuing to champion the understanding that investing early for these children will reduce the cost on services over the long term. We would like to see some clear criteria applied to children accessing this level of intervention, targeting key skill development and capacity building of all of those in the children's lives to support improvement in developmental milestones to be generalised in each child's natural settings. This will need to include an onus on the service provider to upskill the community to better include children on the Autism Spectrum (i.e., not about 'fixing' the child but about improving the environment to better include all children).

We understand that highly intensive therapy can raise conflict with the NDIS principle of promoting inclusion if applied long-term. We would argue that for some children short bursts of highly intensive therapy are integral to their development, and subsequent generalisation of a new skill which then promotes inclusion across many settings.

Response to proposed changed entry pathways (s25)

The proposed changes to the entry pathway for children into the EC Approach and into the Scheme is one of the critical elements of the proposed reset and as such, the Benevolent Society would like to make some specific comments in this regard.

The Benevolent Society supports a number of the elements as proposed, that appear to follow a best practice approach to early childhood development. This includes a focus on functional assessment rather than a medical diagnosis and ongoing assessment to allow for more fluid approaches to the provision of support.¹ As an EC Partner, we look forward to having the opportunity to work intensively

¹ This does not imply full support for Independent Assessments. Further information on our position on Independent Assessments can be found later in the document.

with young children and their families to determine the best path forward considering their individual circumstances.

There is a concerning lack of detail and transparency on the operation of the proposed change in the Project Consultation Report. This limits the level of response; however, we have identified a number of risks on the proposed approach that we believe must be considered and addressed.

Firstly, the proposed approach, if not implemented carefully, risks **bottleneck and duplication** through the implementation of a single access point through the Independent Assessments. While the proposal to situate the assessment function and workforce in the EC Partner organizations is supported, the need for regular assessments for ALL young children creates a risk of delay and a return to significant waiting periods unless fully resourced. It further risks the need for families and children to undertake multiple and repeated assessments, even where diagnosis and assessment of permanent disability is clear. Further mitigation of this risk (beyond resourcing) could include the implementation of a streamlined approach for some children where a medical diagnosis of an impairment with lifelong consequences appears to be a sensible option.

VIGNETTE 2 – Duplicating Services and Creating Unnecessary Bottlenecks

A family spends time (and potentially money) having their child assessed by a specialist regarding some concerns they have. The specialist makes a diagnosis that was previously listed as likely to meet the disability requirements to access the NDIS and refers the family to the local EC Partner. The Partner then tells the family that despite this diagnosis clearly demonstrating lifelong functional impairment, the family must wait to undergo an additional Independent Assessment to ascertain the child's need to access the Scheme. The family is confused about the diagnosis; they feel that this is another hoop to jump through to demonstrate their child needs support; they are now uncertain of the level of supports they will receive through the Scheme; the specialist is upset at the EC Partner for 'doubting' their diagnosis.

The proposed approach may result in less **families seeking medical advice** from paediatricians or health specialists as they do not need to seek a diagnosis prior to accessing ECEI. As a result, there is a risk that families and children will be missing out on important early diagnostic and medical expertise – perhaps identifying underlying medical concerns that may be treatable and result in improved outcomes for young children. While EC Partners may be able to make some connections, we do not have the qualifications to do the medical investigation.

VIGNETTE 3 – Disincentives to Seeking Medical Assessment

A family is concerned about the progress of their child against a number of developmental milestones. Having researched the process of accessing ECEI services, the family learns that their child will need to undergo an Individual Assessment. Not wanting to delay access to ECEI supports, the family seeks support through the EC Partner, forgoing assessment from paediatricians or health specialists. As a result, the family misses out on important diagnostic and medical expertise to help identify an underlying medical concern informing the delay. Without the qualifications to do the required medical investigation, the EC Partner does not pick up the rare syndrome (e.g. Angelman Syndrome) that is causing the delays as it requires genetic testing to identify. Had this been condition been found earlier,

more intensive intervention would have been recommended.

This also highlights the importance of timely and integrated triaging (and intervention) by the EC Partner alongside State Health systems. The issue of families being assessed by doctors and allied health while also seeking access to ECEI and consequently enduring multiple retelling of their story and multiple/duplication of assessments is not cost effective nor best practice for these families. The Benevolent Society advocates for an approach that enables families to share assessment information and therapy outcomes across State health and education systems, creating a broader model of service delivery that wraps around a family throughout their transitions and an integrated access point for these services.

3.2. General questions

Do you have any specific feedback in relation to:

- the increased focus on STEI outside of access to the Scheme
- the proposed increase in age range for the EC Approach from under 7 to under 9 years of age,
- the desire to see more successful transitions from the Scheme to the next stage of life.

As outlined previously, given challenges with early implementation of the ECEI Approach it is now timely to examine the operations of the Approach and make changes in line with a process of continuous improvement. The early challenges have created a range of views and perceptions of the ECEI Approach and the NDIS generally. Regardless of systemic change this requires a revised and renewed communication strategy that seeks to build a common understanding of purpose, approach, and operations. This is good practice across any human services system or program.

The increased focus on STEI is aligned with evidence based, best practice, early intervention. Indeed, this is the work that The Benevolent Society sought to undertake in undertaking the role of the EC Partner for the south-east Queensland region.

The recommendation to increase the capacity of EC Partners to undertake this work is supported. The inclusion of appropriate resourcing and key performance indicators in Partner contracts is supported as current contract arrangements do not provide adequate resourcing for this activity. A key risk remains however, that EC Partners become the new 'silo' delivering short term intervention, continuing the overreliance on the Scheme. There is a need to emphasise supporting the child to access mainstream supports and deliver short-term interventions in these 'natural settings'.

A change of name provides an opportunity to clearly identify the 'reset' and signal a change in approach and strategy. This is critical, however, any change of name and/or change of terminology risks creating confusion. A clear and consistent naming strategy and a clear communication strategy is crucial if stakeholders, parents, service providers are to understand the new approach.

Change in Age

The change in age range brings Australia into line with World Health Organisation (WHO) regarding early childhood interventions and is consistent with a range of mainstream services and community

programs. This will effectively reduce confusion, simplify transitions/linkages and make the system far easier to navigate for all. Additional resourcing will be required to support the increased client group and workload.

“Children were being forced to transition to LAC supports which are very different, alongside transitioning into school which is an overwhelming time for parents. It didn’t match with what the children’s needs were.”

The Project Consultation Report notes that STEI will only apply for children up to the age of 6. It is unclear what the arrangement will be for children aged 6-9 years, beyond “tailored Initial Supports offer ensuring appropriate community and mainstream supports.”² There is an important sector leadership role for the EC Partner to improve service integration and smoother transitions particularly with the education sector.

Focus on exiting the system

A focus on children achieving developmental milestones and goals is strongly supported. However, it is critical that families and children receive all the supports they need now and into the future, be that through mainstream services or a return to the Scheme in the longer term. The desire to see more transitions from the Scheme should not result in a focus on pushing children and families away from services and supports they need or create perceptions of scarcity and rationing that occurs in some other schemes. It is critical that EC Approach and the Scheme is an accessible safety net available for all who need it.

Mainstream services are currently challenged in supporting children with additional needs, particularly health and education. This has resulted in ECEI currently holding services that should be able to transition to other service providers. The desire to see more children transition from the Scheme should be accompanied by a complementary strategy to work in an integrated way across jurisdictions and sectors, to build capacity and collaborative practices alongside communities and service systems.

How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:

- best practice
- capacity building
- natural settings, and/or
- evidence.

Greater communication efforts are required from the Agency to educate the community about the Scheme in general, and in particular common terms and language used, including in ECEI such as; best practice, capacity building, natural settings and evidence. However, these are not the only terms that parents (and participants) struggle with. The Benevolent Society would highlight use of “reasonable and necessary’ as providing challenges, particularly given the change in how this is applied from the EC

² See page 86, Project Consultation Report

Approach to the Full Scheme. Co-design processes with parents, participants, peak bodies and services would support the creation of effective communication tools with a shared understanding of their use.

Transparency in reasonable and necessary decision making should be a focus, with clear communication provided to families on why reasonable and necessary decisions have been made. Using the knowledge the scheme now has from providing many of these decisions, case studies and rationales should be available to families and partners. These should explain commonly requested items and include the circumstances in which these may or may not be approved. For Example:

- Swimming Lessons
- Sensory Tools
- In home support and Respite
- The interface between Inclusion Supports and supports available from NDIS for children to attend mainstream early childhood settings full time
- Intensive supports for children with Autism
- iPads
- Motor Development equipment

All information must be written in plain English and using graphic interpretations shifting away from technical, medical or bureaucratic language. If the terms are difficult to explain, they may be the wrong words. It should not be the responsibility of parents to understand, but for the system to use words that are understandable by parents. All communications should be checked for readability.

Given the diversity of EC Partners across the country, development of a standardised information pack, matched with online content, could streamline expectations, provide clear definitions and act as a single source of information. As part of this information pack, consider the tools that have already been developed in the roll out of the Early Days program. A series of “My Child” workshops could be created that parents attend in person or virtually, from their first point of contact for e.g.:

- My Child and their Developmental Milestones
- My Child and a new Diagnosis
- My Child and the NDIS
- My Child and Early Speech development
- My Child and understanding their behaviour
- My Child and choosing the right service provider
- My Child and going to school
- My Child and going to day care

Partner staff could be then trained to deliver these sessions across the nation as a part of their initial supports roll out. All communications tools should be co-designed with parents, participants, peak bodies and services as applicable.

3.3. Support with achieving goals

What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?

The Benevolent Society recommends frequent 'check ins' with families and carers on progress against goals and developmental milestones. In our view, this should be six monthly at the very least. In our other Child and Family services our practice includes quarterly engagements. During the early years, children can develop very quickly and inconsistently across time. Progress can occur very quickly or alternatively, services can be ineffective and if not resolved, be used for too long. It is critical that systems allow for flexibility and rapid adaptability. It is important that check-in processes, including annual reviews are undertaken with the clear purpose of assessing progress and determining future action. This should not be primarily for the purposes of transitioning out of the Scheme. Service providers should review progress regularly and provide EC Partners with an update. At this point EC Partners can also check in with families on how they are finding their provider as many families do not realise they have choice and control and can change provider and/or type of service delivery.

This will be particularly important in the early period of implementation of the STEI as families and providers adjust and learn. In our experience, many providers are not aware of the existence and benefits of a short-term intervention approach. Intensive communication and engagement may be needed to support increased referrals by service providers to STEI rather than to the Scheme.

It is important to consider 'check-ins' in the broader context of assessment and review and ensure that children and families are not being perpetually assessed.

Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?

Information on progress belongs to the family, and a consistent and mandatory reporting framework empowers parents and carers to seek information; understand progress; and make informed decisions. Currently it is the ECEI key worker's role to support the family to collect reports, but inconsistency of content and process hinders an effective process.

It is important to be clear that provider reports only provide part of the story. Provider reports must be read and understood in the context of a whole-of-family plan and in conjunction with a parent's report; and wherever possible include the voice of the child.

How can we better support families to connect with services that are either funded or available to everyone in the community?

As an existing EC Partner, we support the recommendation to increase the hours of flexibly applied implementation support. The Benevolent Society is committed to working flexibly to support children and families to work across and navigate through complex systems. To date, contract and resourcing constraints have prevented us from undertaking this task to the extent required to meet positive outcomes for families and children. We agree that while support coordination provides a valuable role under the Scheme, there is a need for specialist coordination for children. Specialist EC Partners have

both the experience working with young children and their families, as well as deep knowledge of the early childhood service system.

There is also a need to work alongside the community to be more inclusive of children with a disability. Many children want to be able to access mainstream and community supports but are often excluded physically, socially or emotionally. As an example, in our experience families are often told that they cannot attend day care unless they have 1:1 supports. As this is not funded through the Scheme, there is a need to work with these centres to make the modifications necessary to include these children including applying for funding through the Inclusion Support Program

Peer to peer support

Peer support networks are a valuable and important tool that provide dual outcomes of connection and capacity building. There are a range of strategies that can be implemented to support families to connect with services, however they cannot be the only strategy. It is important that we recognise that all stakeholders in the EC Approach have a role to play in connection – not just families.

Other strategies that should be considered include:

- Dedicated teams and directories to provide streamlined and consistent information
- Build on existing information and referral services where they exist e.g. Family and Child Connect
- Build on existing peer networks and organisations such as Queenslanders with a Disability Network (QDN)
- Build the capacity of service providers to understand other options in the community

EC Partners can play a critical role in supporting streamlined information and referral pathways, if properly resourced to do so. However, this should augment and support existing efforts at the state/territory, or indeed at the community level.

How can we make the process of transitioning out of the NDIS something to celebrate?

Across all of our work, the Benevolent Society defines success as when families no longer need us in our lives, or when they have the support they need. It is important to have this conversation at the beginning of any intervention and the conversation should continue throughout. Celebrating milestones can therefore occur throughout the period of support and should definitely include transitioning out of the Scheme.

Language is important, to differentiate the proposed new EC Approach it will be critical to find and use specific language that differentiates the approach from the broader Scheme. This includes “celebrating transition” from the EC Approach; “meeting milestone”; “being developmentally in line with their peers”.

As outlined earlier, shortfalls in the mainstream service system, whether real or perceived, create anxiety for parents and carers as they contemplate moving out of the Scheme. If transition out of the Scheme is to be a clear celebration, it is important that parents are able to feel confident that mainstreams systems will support them, and that additional support is available, as necessary.

Perceptions of parents as seeing the Scheme as a 'golden ticket' ignore the very real concerns parents have that should they transition from the scheme they will lose the safety net that has been so important to the wellbeing of their family.

The NDIS and the EC Approach exist within the broader service systems and within communities. Our experience is that NDIS has inadvertently created more silos. Indeed, in some instances it is the predominantly state based supports of health and education that have seen the Scheme as a 'golden ticket' that is responsible for children with disability or who are developmentally delayed.

"It's a graduation rather than a loss – moving into the mainstream should be celebrated, but parents are holding on for dear life because there are not enough services outside of the Scheme."

A funded transition plan for the family when transitioning out of the Scheme is welcomed although some flexibility around time frames will be required. This would also need to include some onus on the service provider on building the capacity of mainstream services to be able to continue to utilise the strategies that have proven successful throughout the period of intervention.

3.4. Targeted support

If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?

While our current EC Partner role is confined to South East Queensland, our overall service footprint takes in a number of rural and remote areas across Australia, providing us with insight into the challenges and opportunities that exist in these areas.

The challenges of delivering in rural and remote areas will require a combination of approaches tailored to meet the needs of individual communities and people. The place-based approach as outlined in the Project Consultation Report is supported, noting that these are usually long-term collaborative efforts that will require flexibility in approach to meet the needs of the community. In particular, it is important that these approaches are provided with the flexibility to respond – that may require changes in operational guidelines or policy. We agree that it is important not to compromise the basic tenets of the Scheme, however we encourage the Agency to provide flexibility wherever possible to support local communities to achieve outcomes for children and families.

The two main and consistent barriers to access to services are distance and financial resources. Removing these barriers is critical to support equitable access to support for children and families in rural and remote areas. COVID-19 has shown us how systems and services can adapt to providing support remotely. A shift to online and telephone delivery provides opportunity for increasing services to rural and remote areas.

Delivery through outreach teams provides another opportunity, however caution must be taken on perceptions of FIFO delivery. As an alternative, funding transport, accommodation and staff to support attendance in the city is also an option. This would need preparation and robust support on the ground

from EC partners and services who have built trust and rapport with families in a bid to normalise the process. This will be essential so that families do not feel stigmatised or perceive it as an exceptional intervention.

The pricing schedule needs to adapt to reflect the full and reasonable cost of delivering services to these communities, including costs for travel and accommodation, whether this be for the service provider or the child and family.

As outlined previously any activity in First Nations communities must align to the approach undertaken in Closing the Gap. Solutions in these communities (urban, rural and remote) must be developed and owned by the community, and all efforts made for delivery to occur through community-controlled organisations. This is more than the “engage in consultation” that is referenced in Project Consultation Report.³

How can our Early Childhood partners and mainstream services best support peer-to-peer connections?

Peer-to-peer connections, where possible, should be led and supported by peer-led organisations. The Agency could resource these organisations to undertake the work. As a peer-led organisation here in Queensland, Queenslanders with a Disability Network (QDN) plays an essential role in the system by leading and undertaking a range of peer support and advocacy activities. There are a number of other peer-led models that could be examined for replication/adaptation.

Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?

The Benevolent Society is committed to co-design processes and is interested in supporting the development of an approach to make peer-to-peer networks more accessible. It will be critical that any co-design includes children (where possible), their families, people with lived experience and organisations with expertise in peer led strategies.

How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?

As a service provider delivering Early Years Centres (EYC), The Benevolent Society wanted to participate in the ECEI to support integrated ways of working across service systems – engaging families who are experiencing disadvantage through the EYC and wrapping early childhood intervention support as needed. However, the initial implementation of the EC Partner approach, and the immediate emphasis and workload of supporting the transition of children into the Scheme has to some extent, isolated the EC Approach from the broader service system.

Engaging with people who may be experiencing vulnerability is best done by organisations and services that are trusted and where there is an existing relationship. This is highly context specific – to the context of the individual, the family and the community. This trusted service could be a school, a GP, a community centre, a community organisation. Strong partnerships between the EC Partner and a range

³ See page 80, Project Consultation Report

of organisations in the community can support effective identification of children who may benefit from EC support. For First Nations and culturally and linguistically diverse communities, engagement with specialist cultural services is critical. As outlined previously, particularly in First Nations communities (remote, rural and urban) engagement and service delivery is best led by community-controlled organisations.

As an example, The Benevolent Society has built a successful partnership with the Institute for Urban Indigenous Health (see case study below) that has enabled us to reach into the community and gain the trust of many families who would not otherwise access our service. This work takes substantial time and resources to create. The Benevolent Society sees this as a core part of an effective EC Approach and support recommendations to ensure that EC Partner contracts include sufficient resourcing and relevant KPIs to support this partnership work to occur.

CASE STUDY: Partnership – The Benevolent Society and Institute for Urban Indigenous Health (IUIH)

This partnership represents best practice in promoting the economic, political, and social inclusion of Aboriginal and Torres Strait Islander people through supporting self-determination and ensuring that Aboriginal community-controlled organisations are involved in the decision-making process for the provision of supports in their communities. Through this partnership the Benevolent Society has grown our ability to reach into the community and gain the trust of many families who would not otherwise access our service.

Activities undertaken:

- Establishment of an ECEI First Nations working group
- Continuation of streamlined referral pathway
- Support to obtain documents for access through IUIH and Elders networks
- Partnership Employee attends all ECEI meetings where the family have requested an Aboriginal or Torres Strait Islander worker
- Partnership Employee supports capacity building for the team around best practice in First Nations engagement
- Joint community events including extension of our Caravan park group into an additional Caravan park
- Co-location of Partner Employee and The Benevolent Society CD Snr Practitioner

A key element of the partnership has been for Benevolent Society staff to undertake cultural training through Yarning Circles to support understanding of Aboriginal history and the injustices that still occur today.

Looking forward the partnership aims to:

- Develop a best-practice approach to supporting Aboriginal and Torres Strait Islander parents and carers of young children to access Early Intervention Supports
- Increase awareness in Aboriginal and Torres Strait Islander families about the supports that are available to young children with developmental concerns
- Improve timelines for Aboriginal and Torres Strait Islander families between seeking access to the Scheme and an approved plan
- Improve utilisation of funds in an approved plan to support improved outcomes for Aboriginal and Torres Strait Islander children and their families
- Improve reported experience of families from Aboriginal and Torres Strait Islander backgrounds that access the ECEI approach

- Increase the capacity of mainstream and community services to provide opportunities for Aboriginal and Torres Strait Islander children with developmental concerns to access their community
- Report on key achievements and share the outcomes of the project in forums that will support furthering the understanding that funding Aboriginal Controlled Community Organisations to work with Aboriginal and Torres Strait Islander families is an integral element to reconciliation.

Outcomes achieved: In the December quarter, data ⁴ shows an

- Increase from 6.5 % to 6.7% of all plans approved in the last 12 months in the Brisbane and Moreton Bay LGAs identify as Aboriginal or Torres Strait Islander
- Increase from 5.2% to 5.5% of the Benevolent Society’s current cohort of Tier 2 customers receiving initial supports or short-term intervention in the last 12 months identify as Aboriginal or Torres Strait Islander
- Improved average time between an access met decision and approved Plan for children who identify as Aboriginal or Torres Strait from 58.08 days to 53.59 days for the Brisbane LGA and 58.28 days to 57.28 days for the Moreton Bay LGA
- A reduction from 28% to 27% of plans for Aboriginal and Torres Strait Islander children in the Brisbane and Moreton Bay LGAs that have not been utilised at all in the first 3 months.

3.5. Tailored Independent Assessments (IAs) approach

It is recommended that the Agency implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions. Specifically, we are planning to:

- Commission Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce
- Use IAs for young children above 1 years of age
- Use the following tools (as outlined in an appendix to the previously published Independent Assessment Tools Paper):
 - Ages and Stages Questionnaire (ASQ-3) OR Ages and Stages Questionnaire -Talking About Raising Aboriginal Kids (ASQ-TRAK)
 - PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy)
 - Vineland-3 Comprehensive (Interview Form)
 - Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years
 - Participation and Environment Measure - Children and Youth (PEM-CY) for children 5+ years

Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?

The Benevolent Society supports consistency in assessment. We also support a tailored EC Approach to Independent Assessments (IA) which would provide for specialist early childhood assessment including access to allied health professionals. However, the Project Consultation Report provides little detail on the implementation and operations for the IA noting that “the Agency will continue to refine how independent assessments will be implemented for young children and families ahead of their introduction... “Based on the limited information provided, The Benevolent Society makes the following comments:

- Part of the puzzle: currently assessment tools are used by EC Partners as a contribution to create a full picture of capability, functionality and therefore support needs within a broader family,

⁴ All data sourced from NDIA (PANDA) data analysis

community and system context. Use of a tool as a stand-alone, single point of assessment, may limit the ability of EC professionals to apply their own professional lens across the entire support system of the child.

- **Workforce:** there are significant workforce issues in relation to administering and analysing the assessments. This workforce is not currently available to all EC Partners and will require significant resourcing. In some instances, the assessment tool may require clinical skills/qualifications.
- **Flexibility:** there is a need for there to be flexibility in the tool used, including flexibility to add new tools to the list available.
- **Culturally Appropriate:** some of the assessments are not appropriate for First Nations or culturally and linguistically diverse populations.

In regard to the specific tools identified, The Benevolent Society has not had sufficient time to assess each tool. However, we do offer the following comments:

- **PEDICAT:** is not well received by many families. It is not Australian, making many of the questions inappropriate. Many of the questions are inappropriate for children in the younger age bracket. The use of this tool should be limited to a Child Development specialist and/or Occupational Therapist with a professional lens that can adapt the questions to the situation and draw much of the required information from observation of children at play and in their natural settings. All administering of this tool should have a certain level of training to ensure its appropriate application.
- The tools would have to be delivered in culturally appropriate ways and support engagement of families and children

A key feature of the ECEI/EC Approach is a family centred approach, that considers the support needed by both the child and the family to ensure full functional capability of the child in the context of their family and community. An assessment that is solely focussed on the functional capacity of the child appears to address only part of the core tenets of the EC Approach. Furthermore, it appears to align with a medical model for disability and promotes deficit-based assumptions, planning and subsequent service choice for families. Further, it is important that assessment to occur in a range of settings, particularly natural settings which are familiar to the child and family.

Many children and families are unfamiliar with assessment processes. It is strongly recommended that provision is made for families to use personal advocates to support them in the assessment process. To not do so, risks the key purpose – that of consistency and equity – as resulting assessments are based on the individual understanding and response to the question.

3.6. Greater transparency on providers of best practice

It is recommended, from the previous consultation leading to this paper, that a range of mechanisms be considered to enhance providers' compliance with best practice standards and to provide greater transparency on which providers, both registered and unregistered, are following Early Childhood Intervention best practice.

What mechanisms do you think could help achieve this?

Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?

What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?

- Provide greater information to families about the benefits of using providers registered by the NDIS Commission.
- Establish an industry-led 'best practice accreditation system'.
- Establish a 'quality feedback / rating system'.
- Make registration with the NDIS Commission mandatory for all providers operating in the EC space.
- Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.

The Benevolent Society agrees that the current ECEI Approach often does not support best practice approaches to early childhood intervention. The market-based mechanism based on use of a pricing guide to drive best practice does not support the collaborative, long term family centred approach that is articulated through the literature and experience of specialist providers.

The current registration and auditing process for providers is complex and expensive, effectively excluding all but the larger providers. Our experience in the broader NDIS context is that many previously registered providers are now deregistering due to the increasing complexity and cost. Thin markets exist across the EC Approach, particularly in allied or specialist health services and in rural and remote areas.

As such, the Benevolent Society does not support the introduction of additional barriers to entry for providers or the restriction of access to providers to only those that are registered. We are interested in supporting the Agency and others to explore options for improving service quality and supporting parents and carers to make decisions around provider selection through improved information and guidance. This could include:

- An opt-in star rating system for providers
- A 'traffic light' system for interventions (not providers)
- Increased and improved information for families – this would need to be in plain English, multiple languages, including Aboriginal and Torres Strait Islander languages, and be tested for readability.
- Communities of Practice – EC Partners could be supported to facilitate providers to come together for a range of professional development experiences.

One option that has emerged through our internal consultations is the development of a third, lower level of 'registration', that would enable a minimum standard but would not require providers to go through verification or certification. This could be an inclusive, self-regulation approach that could include a 'declaration' of support for the NDIS Code of Conduct and a possible new charter for best practice EC supports. Peak bodies such as Reimagine Australia would be well placed to lead the development of the new Charter supported by research organisations and a range of providers, based on the EC best practice principles and informed by practice experience.

While this would not have the audit requirements that goes along with registration it would at least ensure an awareness of the ethos of the scheme without precluding smaller providers (particularly in

rural and remote areas) from delivering much-needed services. It would also empower families because potentially the charter would help them self-advocate if their services aren't meeting their needs.

The Benevolent Society is concerned about the recommendation to empowering EC Partners to provide families with clear advice about providers. While we agree with the Project Consultation Report that the provision of "objective, evidence-based advice will enable them [EC Partners] to be more responsive to requests from families"⁵ we believe this should occur at the intervention level, rather than at the provider level. This would reduce the risk of conflict of interest for individual EC Partner staff. This could be accompanied by the 'traffic light' system for rating interventions.

Reimagine Australia would be best placed to lead the design of any future system for supporting best practice. As the leading Australian body for early childhood outcomes for young people with a developmental delay or a disability, and their families, Reimagine Australia have significant expertise in embedding best practice and inclusive systems.

Any publicly available information to support and inform about evidence-based best practice approaches need to be in plain English and in multiple language including Aboriginal and Torres Strait Islander languages.

4. Conclusion

To achieve sustained, positive outcomes for children and families, the EC Approach must be reset not solely in a programmatic frame of reference. A systemic approach must guide this reset in order to maximise the benefits for children and families that arise from integrated support systems.

With greater workforce capability, and better integrated early support systems for children, we all have the opportunity to improve resilience and positive outcomes for children and families within the EC Approach. Practice experience and evidence shows that early support, 'stacked' across all domains of wellbeing improves outcomes for children*. For instance, therapeutic or allied health supports to children with disabilities may have limited impact if their material needs, such as housing and family income, are not met. Early interventions need to response to all domains of well-being.

⁵ See page 91, Project Consultation Report

Appendix 1: Response to Recommendations.

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
<p>1: Explain, rename and promote the new NDIS Early Childhood approach</p>	<p>“Intervention” has negative connotations for some in sector and “gateway” undermines value of early childhood supports</p>	<p>“Early Childhood approach”) to support clear communications</p>	<p>Partially agree: A new name provides a clear signal of change. However any change of name and terminology risks creating confusion. A clear and consistent naming strategy is required if stakeholders, parents, service providers are to understand the new approach.</p>
<p>2: Clearly and consistently, communicate the intent of the Early Childhood approach and the Agency’s support for best practice</p>	<p>More limited communications and published materials contributes to inconsistent understanding of best practice</p>	<p>Active communications and growing repository of published materials promotes consistent understanding of best practice</p>	<p>Agree. A clear and consistent communication strategy is critical to communicate any system or program change.</p>
<p>3: Develop and publish new Early Childhood-specific Operating Guidelines</p>	<p>Integration of guidance on early childhood into general Scheme materials increases risk of applying adult-centric approaches to young children and makes Early Childhood Early Intervention approach content harder to find</p>	<p>Suite of distinct Early Childhood approach-specific OGs to provide clarity on best practice approaches to young children and make Early Childhood approach content easier to find</p>	<p>Agree. The current content available is mainly targeted at adult cohort and more EC specific content is required. In particular, there is a need for EC specific guides pitched specifically at the types of funding and FAQs for each category that is EC specific OGs could focus on how children move beyond the program and not always into NDIS plans. It is important that OGs provide enough scope for service providers to genuinely work with families to develop their goals, establish supports, and create sustainable outcomes.</p>
<p>4: Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported</p>	<p>NDIA workforce serves participants across all ages, increasing risk of applying adult-centric approaches to young children</p>	<p>Distinct NDIA workforce specialised in supporting young children and their families in line with best practice</p>	<p>Agree. This will help embed the changes NDIA are making to the Early Childhood space and streamline processes for children and minimise discrepancies. Important to include EC delegates within the National Review Team and Internal Review Team to prevent undermining of EC Partner decisions. In addition, staff need to be mindful of the role of Supported Decision making to empower children to be an active part of decision making. If a new workforce is required, consideration needs to be made to the pressures additional NDIA EC workforce will place upon the EC workforce generally.</p>

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
<p>5: Continue to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.</p>	<p>Collaboration only occurring with EC partners at a local level in the communities</p>	<p>A more collaborative and enhanced relationship with health and education services across the early childhood sector</p>	<p>Partially agree. There is a strong need for better collaboration and alignment of services across jurisdictions. This needs to occur at the local level as well as at the strategic government level.</p> <p>In our experience EC Partners are not empowered to take a lead locally to engage with mainstream services – this occurs predominantly through the NDIA. We see this is a critical gap in our capacity to truly meet the objective of the EC Approach – to work alongside, not independent of, these services.</p> <p>The development of the National Disability Strategy is an important tool in building collaboration at the strategic level. However, the success of any strategy is reliant on good implementation and the establishment of meaningful relationships across systems.</p>
<p>6: Consider a range of mechanisms that will enhance compliance of providers with <i>NDIS Practice Standards on Early Childhood Supports</i> and increase awareness by families of providers that adopt that best practice framework.</p>	<p>Concerns that some providers may not be following best practice standards and that there is limited information to help families choose between providers</p>	<p>Greater compliance with and transparency over which providers are following best practice standards to help families make informed choices about which provider to use</p>	<p>Partially agree. Action is required to support best practice across the EC Approach. However current registration and auditing process are complex and expensive and increasing compliance with these risks reducing provider numbers and therefore service levels.</p> <p>Therefore, the Benevolent Society does not support the introduction of additional barriers to entry however we are interested in working with the Agency to explore options for improving service quality and supporting parents and carers to make good decisions. Some options have been provided in the body of our submission (page 19)</p> <p>Any publicly available information to support and inform about evidence-based best practice approaches need to be in plain English and in multiple language including Aboriginal and Torres Strait Islander languages.</p>
<p>7: Improve sector wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from</p>	<p>Culturally safe information and advice is not always available to all families from diverse communities</p>	<p>Improved understanding and tailored culturally safe information and advice available to all families regardless of community</p>	<p>Agree. Engaging with people who may be experiencing vulnerability is best done by organisations and services that are trusted and where there is an existing relationship. This is highly context specific – to the context of the individual, the family and the community. This trusted service could be a school, a GP, a community centre, a community organisation. Strong partnerships between the EC Partner and a range of organisations in the community can support effective identification of children who may benefit from EC support. For First Nations and culturally and linguistically diverse communities, engagement with specialist cultural services is critical. Particularly in First Nations communities (remote, rural and urban) engagement and service delivery is best led by community-controlled organisations.</p>

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
early interventions support.			It is important that a partnership approach is taken with mainstream services to ensure that children benefit from both EC and mainstream expertise and capacity.
8: Implement tailored methods of delivering supports for young children and their families living in remote and very remote areas to strengthen access to services.	Insufficient level of supports and access to services in some remote and very remote areas	Satisfactory levels of supports and access to services in all remote and very remote areas	Agree. We support place-based approaches that provide long term collaborative partnership to co-design local solutions. It is important that the Agency provide flexibility and a long-term view of such collaborations. In Aboriginal and Torres Strait Islander communities' solutions must be developed and owned by the community and all efforts made for delivery to occur through community-controlled organisations, in line with the Closing the Gap partnership. This is more than "engage in consultation" and must include collaboration and where possible shared decision making.
9: Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions	No consistent assessment approach; lack of robust tools contributes to inconsistent, unfair and inequitable decision making	IAs administered for young children to support more consistent, fair and equitable decision making	Partially agree. The Benevolent Society supports consistency in assessment and that any assessments must be undertaken by early childhood experts. The Project Consultation Report does not provide detail on the operations of IA; however, we have noted a number of comments in the body of our submission (Page 17). These include comments on the need for flexibility; cultural appropriateness of various tools; workforce implications and more. A key feature of the ECEI/EC Approach is a family centred approach, that considers the support needed by both the child and the family. An assessment that is solely focussed on the functional capacity of the child appears to address only part of the core tenets of the EC Approach. Furthermore, it appears to align with a medical model for disability and promotes deficit-based assumptions, planning and subsequent service choice for families.
10: Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability.	Benefits not being realised consistently across vulnerable families	Maximised benefits of early intervention for children in vulnerable families	Agree. Engaging with people who may be experiencing vulnerability is best done by organisations and services that are trusted and where there is an existing relationship. This requires building strong partnerships with these organisations. The Benevolent Society sees this as a core part of an effective EC Approach and support recommendations to ensure that EC Partner contracts include sufficient resourcing and relevant KPIs to support this work to occur, noting the significant resource required for activity to be successful.

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
<p>11: Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.</p>	<p>Families not consistently receiving peer support</p>	<p>Families empowered by consistently receiving access to peer support networks</p>	<p>Agree. Peer to peer networks are an important tool providing dual outcomes of connection and capacity building. However, they cannot be the only strategy and it is important that we recognise that all stakeholders in the EC Approach have a role to play in connection – not just families. It can be challenging for some families to engage in these types of face-to-face support groups. Online platforms would be a great option for some families. Explore how these could be facilitated as a Partner to ensure positive, accurate and solutions focused information.</p>
<p>12: Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer</p>	<p>Modest service level limits viability and effectiveness of STEI offer</p>	<p>Higher service level enhances viability and effectiveness of STEI offer</p>	<p>Agree. The increased focus on STEI supports alignment with evidence based best practice early intervention. Indeed, this is the work that The Benevolent Society sought to undertake in undertaking the role of the EC Partner for the south-east Queensland region. The recommendation to increase the capacity of EC Partners to undertake this work is supported. The inclusion of appropriate resourcing and key performance indicators in Partner contracts is supported as current contract arrangements do not provide adequate resourcing for this activity. A key risk remains however, that EC Partners become the new ‘silo’ delivering short term intervention, continuing the overreliance on the Scheme. There is a need to emphasise supporting the child to access mainstream supports and deliver the short-term interventions in these ‘natural settings’.</p>
<p>13: Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making. Establish thresholds for key criteria using Independent Assessments.</p>	<p>Inadequate definition of ‘substantial delay in functional capacity’ and ‘extended duration’ drives inconsistent decision making</p>	<p>Clear definition of ‘substantial delay in functional capacity’ and ‘extended duration’ to support consistent decision making</p>	<p>Agreed. The desire to clarify the interpretation of developmental delay to provide certainty and reduce inconsistency is supported. In our experience, the current criteria are subjective and open to interpretation. However, the term has been in use in the broader health, community, and education sectors for some time. It will be important that any clarification does not diverge from common usage and understanding as this risks creating more uncertainty and confusion. It will be important that any clarification is broadly consistent with commonly accepted understanding of the term. Any divergence from these commonly accepted understanding risks creating more uncertainty and confusion. Introduction of new terms should be tested with all stakeholders. Further consultation should be undertaken before finalising any changes.</p>

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
14: Increase the age limit for children supported under the new Early Childhood approach from 'under 7' to 'under 9' years of age	Under 7 years of age, ending before school transition is complete	Under 9 years of age to provide continuity of support throughout transition to school	Agree. The change in age range brings Australia into line with World Health Organisation (WHO) regarding early childhood interventions and also creates consistency with a range of mainstream services and community programs. This will effectively reduce confusion, simplify transitions/linkages, and make the system far easier to navigate for all. Additional resourcing will be required to support the increased client group and workload. The Project Consultation Report notes that STEI will only apply for children up to the age of 6. It is unclear what the arrangement will be for 6-9-year olds beyond "tailored Initial Supports offer ensuring appropriate community and mainstream supports. ⁶ There is an important sector leadership role for the EC Partner to improve service integration and smoother transitions particularly with the education sector.
15: Use the early intervention criteria, under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children	Children enter through both s.24 and s.25, creating confusion over purpose of EC Approach	Children enter exclusively through s.25, with clearer focus on prevention and early support	Partially Agree. The Benevolent Society supports a number of the elements as proposed, that appear to follow a best practice approach to early childhood development. This includes a focus on functional assessment rather than a medical diagnosis; ongoing assessment to allow for more fluid approaches to the provision of support. ⁷ As an EC Partner, we look forward to having the opportunity to work intensively with young children and their families to determine the best path forward considering their circumstances. There is a concerning lack of detail and transparency on the operation of the proposed change in the Project Consultation Report. This limits the level of response; however, we have identified a number of risks on the proposed approach that we believe must be considered and addressed. The body of our submission identifies a number of risks in the proposed approach (page 7).
16: Increase Early Childhood Partner capacity and flexibility to tailor the level of support provided to families to implement a child's plan and more quickly connect to the	Limited implementation support for plans	Increased support to help family's better implement plans.	Agree. As an existing EC Partner, we support the recommendation to increase the hours of flexibly applied implementation support. The Benevolent Society is committed to working flexibly to support children and families to work across and navigate through complex systems. To date, contract and resourcing constraints have prevented us from undertaking this task to the extent we would desire. We agree that while support coordination provides a valuable role under the Scheme, there is a need for specialist coordination for children. Specialist EC Partners have both the experience working with young children and their families as well as deep knowledge of the early childhood service system. Additional

⁶ See page 86, Project Consultation Report

⁷ This does not imply full support for Independent Assessments. Further information on our position on Independent Assessments can be found later in the document.

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
right supports and services			resourcing is required for this to be successfully implemented including when ensuring participant volumes are calculated in such a way as to account for the additional work.
<p>17: Introduce a ‘capacity building support in natural settings’ item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.</p>	<p>Potential incentive to maximise number of therapy session over best practice sessions in natural settings</p>	<p>Separate line item in price guide to encourage best practice therapy support in natural settings</p>	<p>Agree. Best practice in early childhood intervention clearly articulates a preference for supports to be delivered in a ‘natural setting’, that is in an environment that is familiar to a child. Under the market model of the NDIS, one of the key levers to support changed behaviour by service providers is to incentivise action through pricing. Inclusion of a new line item for capacity building in a natural setting is therefore a positive step. Success of this recommendation will depend on the level of pricing and the inclusion of the ability to compensate for travel time for the service provider. It will also be critical that the term natural settings is clearly defined and easily understood by parents.</p> <p>There also needs to be further preparatory work done with ECEC providers and the state education systems alongside ECEI to support to support better service system integration. Currently there are many blockages for families to be able to access support in mainstream systems (noted natural settings) and pressure on ECEI coordinators to include in-home supports in a plan as access to these ‘natural settings’ is often refused.</p>
<p>18: Publish new guidance about what is considered ‘reasonable and necessary’ when making decisions around support for children on the autism spectrum</p>	<p>Unclear R&N guidelines and weak evidence base driving inconsistent plan budget decisions</p>	<p>Published R&N guidelines for children with ASD, backed by evidence, to support consistent plan budget decisions</p>	<p>Agree with consistent decision making.</p> <p>As the EC Partner the Benevolent Society has firsthand experience working with families and providers within the intensive supports for children with Autism space. We agree that this is a space that has not been clearly defined for families and providers and creates a sense on inequity for families where they may have a child displaying the same level of functional impact of their disability but have not opted to enrol in an intensive program for children with ASD. A transparent approach needs to be provided for families and service providers that clearly identifies the place of intensive supports and in what circumstances these may be approved. Feedback from many families is that this feels like ‘secret NDIA business’ and that if they don’t ask about intensive supports they will never receive them.</p> <p>We agree that it will be important to rely on the evidence available on what best practice in this space is while continuing to champion the understanding that investing early for these children will reduce the cost on services over the long term. We would like to see some clear criteria applied to children accessing this level of intensive supports targeting key skill development and support for this to be generalised in each child’s natural setting. This will need to include an onus on the service provider to upskill the community to better include</p>

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
			<p>children on the Autism Spectrum (i.e. not about ‘fixing’ the child but about fixing the environment to better include all children)</p> <p>We understand that highly intensive therapy can raise conflict with the NDIS principle of promoting inclusion if applied long-term. We would argue that for some children short bursts of highly intensive therapy are integral to the development and then generalisation of a new skill which then promotes inclusion across many settings.</p>
<p>19: Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation</p>	<p>EC Partners implicitly discouraged from providing advice to families</p>	<p>EC Partners empowered to provide advice to families based on clear evidence</p>	<p>Partially agree. The Benevolent Society is concerned about the recommendation to empowering EC Partners to provide families with clear advice about providers. While we agree with the Project Consultation Report that the provision of “objective, evidence-based advice will enable them [EC Partners] to be more responsive to requests from families”⁸ we believe this should occur at the intervention level, rather than at the provider level. This would reduce the risk of conflict of interest for individual EC Partner staff. This could be accompanied by the ‘traffic light’ system for rating interventions outlined in the body of our submission. (See page 18)</p>
<p>20: Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support</p>	<p>Minimal evidence contributes to inconsistent decision making and service delivery</p>	<p>Stronger evidence base to guide decisions and service delivery</p>	<p>Agree. The results of any research or study should be clearly communicated to all people and organisations connected to the EC Approach including informing guidelines or strategies for best practice such as the proposed traffic light system. (See page 18)</p>
<p>21: Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes and transition out of NDIS supports to</p>	<p>Required supports for a child take longer to match their needs</p>	<p>Supports needs are quickly matched to the evolving needs of a child</p>	<p>Partially agree. Annual review processes are important for ensuring that supports meet the evolving needs of a child. However, these should not be undertaken primarily for the purposes of transitioning out of the Scheme, but to understand the needs for support moving forward – be that changing supports or moving to the next stage of life. Across our work, the Benevolent Society defines success as when families no longer need us in our lives or when they have the support they need. It is important to have this conversation at the beginning of the interventions and should continue throughout. There is a need to be mindful of ensuring people are not being perpetually assessed particularly when there is a clear, ongoing diagnosis.</p>

⁸ See page 91, Project Consultation Report

Summary of recommended change	Current state (from Report)	Desired future state (from Report)	The Benevolent Society Position
the next stage of their life.			
22: Ensure providers are using the recently introduced ‘provider outcomes report’, as a mandatory measure	Not all families receive information from providers on how supports have helped their child	All families receive information from providers on how supports have helped their child	Agree. Information on progress belongs to the family, and a consistent and mandatory reporting framework empowers parents and carers to seek the information; understand progress; and make informed decisions. Currently it is the ECEI key workers role to support the family to collect reports, but inconsistency of content and process hinders an effective process. It is important however, to be clear that provider reports only provide part of the story. Provider reports must be read and understood in the context of a whole-of-family plan and in conjunction with parent’s report; and wherever possible include the voice of the child.
23: Offer families of young children a ‘transition out’ plan for up to three months’ duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.	Some families experience unexpected and abrupt termination of funded supports	Optional 3 month transition out plan to promote a warm handover for children transitioning to the next stage of life	Partially agree. Transitions plans are important for supporting parent and children to move onto the next stage of life. However, three months may not be enough, and flexibility may be required. The desired future state of a “warm handover” will be very dependent on the availability of mainstream / community supports. There may be a need to include some onus on the service provider on building the capacity of mainstream services to be able to continue to utilise the strategies that have proven successful throughout the period of intervention.