

# Reforms to sustain and build the NDIS

Submission to the NDIS Review

August 2023

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# The Benevolent Society

The Benevolent Society has been operating since 1813. Our history reflects a passion for helping people live life, their way. We know that anyone in the community could, at some point in their lives, need support from us. We have rigorously campaigned and advocated to create meaningful policy and legislative change for all Australians, especially those at greatest risk of exclusion and disadvantage.

We are unwavering in our conviction that people can build their best lives, even in the most challenging settings, with the right supports and interventions. Our campaigning was integral to:

- Free legal aid
- Age pensions
- Specialist maternity care and establishing the Royal Hospital for Women
- An end to child labour
- The Goodstart Early Learning syndicate
- Early social enterprise entrepreneurship through setting up Social Ventures Australia, and
- Australia's first social benefit bond supporting The Benevolent Society's Resilient Families Program.

The Benevolent Society is a multi-service provider, with services ranging across age groups and cohort types. We provide early childhood services, disability services, services to support older Australians to live well in the community, and services to support people in times of crisis.

The Benevolent Society has a deep and coherent understanding of how service systems interact with each other, the needs of our client groups and how the perspective of clients can be best leveraged into broader conversations. We think about our service delivery in the context of the bigger picture – we understand that no one sector or organisation controls all the levers necessary to deliver choice, control and quality of life opportunities to the people who access human services or to deliver social change.

The Benevolent Society brings a system leadership mindset to all that we do. Complexity demands collaboration: we are better together. Our experience tells us that collaboration between organisations produces the best outcomes for vulnerable Australians, especially when collaborations are grounded in the resources and knowledge of local communities.

# Executive Summary

**The Benevolent Society's vision is for a just society where all Australians can live their best life.**

Fundamental to our work is the understanding that all Australians contribute to the richness of our communities. We recognise the worth, potential, and inherent dignity of every person; and the power of diversity when operating in a complex environment.

**Our experience is as a registered NDIS provider of allied health therapies, behaviour support and support coordination and as an Early Childhood Approach partner.**

The Benevolent Society is one of the largest not for profit disability allied health services in Australia. As an NDIS provider, we have a strong focus on working with complex clients with intellectual disability, autism and who need behaviour support. We became a provider in NSW after the NSW Government allied health and behaviour support services were transferred to our management and we continue the strong clinical governance and practice supervision arrangements built up over many years. As an ECA partner, we have used our deep understanding of child development to assist children with developmental delay to catch up milestones without long term NDIS plans.

**The Benevolent Society welcomes the findings and conclusions set out in the NDIS Review publications to date.**

We are encouraged by the Review's commitment to address problems with the Scheme in the interests of participants and all Australians living with a disability. We agree it is time to move from defining problems to designing solutions that can sustain and build a better NDIS<sup>1</sup>.

**Making the Scheme sustainable will require innovation and collaboration.**

Many of the challenges identified by the NDIS review are complex and hard to solve. Lasting, ambitious and effective reform of the NDIS will only be achieved through solutions generated by a partnership and collaboration between people with disabilities, governments, providers and the wider community.

**This submission will highlight evidence-based solutions that reflect core principles of the Scheme.**

In the discussion below of each example of successes at The Benevolent Society, the analysis includes an assessment of how our practices support principles at the core of NDIS design, namely, 'choice and control' and 'reasonable and necessary'. The Benevolent Society notes that the application of the concept of 'reasonable and necessary' is already a subject of the Review's considerations.

**Our experience is that there are clear opportunities to improve disability services for the benefit of people with disability, particularly children and people with higher needs, as well as maintaining the sustainability of the NDIS.**

Our experience and insight in these specialised areas provide the foundation for this submission, with a particular focus on;

- Scheme access for First Nations people
- Responding to Developmental Delay
- Supporting Clients with Complex Needs, and
- Soft Entry Points and the role of State and Territories.

The Benevolent Society is happy to provide additional detail or information about our comments in this submission if that would be of assistance and would welcome the opportunity to host interested Ministers or officials at our services, to demonstrate how policy and strategy are reflected in service delivery.

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<sup>1</sup> NDIS Review (2023) [What have we heard. Moving from defining problems to designing solutions to build a better NDIS.](#)

# Recommendations

The Benevolent Society recommends the disability reforms include:

- 1. A funded strategy to increase access to services by First Nations people, with:**
  - 1.1. the creation of more partnerships between Aboriginal Community Controlled Organisations (ACCOs) and disability providers,
  - 1.2. funding to increase ACCOs' capacity to independently provide disability services as needed, and
  - 1.3. analysis of NDIA data on access for First Nations people so partnership projects can be commissioned in regions where they are most needed.
- 2. A commitment to create client pathways for children that emphasise the potential to make functional gain through high quality, evidence-based services, particularly for children with developmental delay. If effective these pathways should improve outcomes for individuals and reduce pressure on the Scheme.**

Specific parts of the pathway should include:

  - 2.1. consideration of funding therapy and behaviour support as a bundle, not individual hours, when it is being provided to achieve functional gain. Bundling may assist participants to choose and providers to deliver services based on their effectiveness rather than hours of service. The size of bundles could be linked to evidence about the amount of therapy that would be expected to achieve potential gains,
  - 2.2. funding to train a sufficiently sized workforce with a high degree of competency in relationally informed model of care, and
  - 2.3. analysis of NDIA data to understand the range of therapy hours being used by different groups of children with disability, such as children with developmental delay, and any relationship that can be found with goal attainment and long-term use of the NDIS.
- 3. The establishment of market settings that support multidisciplinary coordinated responses for clients with high needs and that create and maintain an adequate pool of suitably qualified practitioners, with:**
  - 3.1. immediate priority focus on models that fund providers' role in workforce development and create a structured pipeline for allied health and behaviour support workers,
  - 3.2. the creation of an accessible and easy to use mechanism so participants can assess the quality and specific expertise of possible therapy providers.
  - 3.3. a standard way to measure functional gain, co designed with participants, providers and academics,
  - 3.4. a mechanism that allows participants, particularly children, who stop or reduce therapy hours to easily restart services when they reach major transition points such as adolescence, and
  - 3.5. ways for participants, providers and researchers to collaborate on the use and development of evidence on the effectiveness of therapies and behaviour support.
- 4. State and Territory government contributions to disability reform that create a network of locally available soft entry points for families, that integrate universal and targeted services, supports and therapies, including:**
  - 4.1. increased investment to establish new (and expand current) local soft entry points, particularly in lower income communities,
  - 4.2. funding to co-locate multidisciplinary teams that wrap around children and their families, and
  - 4.3. investment in accountability for improved childhood outcomes by establishing, capturing, and publishing a set of nationally agreed measures.

**And that all the above disability reform be governed through a compact between people with disabilities, providers and all levels of government.** Given the complexity of the reform goals, this work requires a partnership approach that will allow ideas to be tested, trialled and scaled in ways that are supported by all stakeholders.



# 1. Access for First Nations People

Improving health and social outcomes for First Nations people requires a commitment to programs designed and led by their communities. It appears the prevalence of diagnosed disability among First Nations people is increasing<sup>2</sup>. Yet, even with growing demand First Nations people are less likely to receive care through the Scheme than non-indigenous people<sup>3</sup>. This situation will only change through the application of a culturally competent, whole of community approach<sup>4</sup>. And a plan by itself is not enough. It needs the right facilitation – led and designed by the First Nations community.

**The Benevolent Society recommends disability reforms include a funded strategy to increase access to services by First Nations people:** with specific scope for more partnerships between Aboriginal Community Controlled Organisations (ACCOs) and disability providers, funding that increases ACCOs' capacity to independently provide disability services, and analysis of NDIA data on access for First Nations people.

## A Genuine Partnership Solution

Solutions that build the strength and sustainability of ACCOs in disability must be recognized. Without sufficient funding and planning, ACCOs simply cannot deliver independent services everywhere they are needed. Building capacity and generating a larger workforce will take time. In the interim there is a crucial allyship role for other mainstream organisations as connectors. It is in this context that the partnership between *The Benevolent Society and the Institute for Urban Indigenous Health*<sup>5</sup> (IUIH) began. IUIH is an ACCO based in southeast Queensland.

Together, The Benevolent Society and IUIH provide a seamless pathway for First Nations clients into culturally safe disability services across southeast Queensland. The partnership reduces barriers to engagement by leveraging existing trusted relationships in the community. This only works because all involved are committed to IUIH as the lead holding the authority across design and leadership. Over the last three years this partnership has lifted the number of First Nations families

## Grandmother's Story<sup>5</sup>

Grandmother has been caring for her granddaughter (5 years) from the age of 3 months in a kinship care arrangement. Both identify as First Nations people. The granddaughter has developmental delays that are impacting on her grandmother's ability to continue to care for her granddaughter.

**The family was overwhelmed.** When the IUIH/TBS ECA Partnership team visit, they identify through yarning that while the NDIS was the family's primary concern additional concerns exist around schooling, mental health, and carer fatigue. The family are becoming concerned about their ability to care for their granddaughter.

**The grandparents were able to access free IUIH supports due to the partnership and warm referral.** They were linked in with a paediatrician and allied health professionals - this flowed to referrals for further supports and allowed Grandmother to gain access to the NDIS through the partnership.

**Moving forward the partnership team connected Grandmother to external support that assisted with the granddaughters' schooling concerns.** One key area was school exclusion with the school requiring the granddaughter to be collected by midday every day. The partnerships team advised Grandmother the school had a responsibility to be inclusive. Another First Nations service was brought into advocate. They organised a community Elder to accompany Grandmother to the school and discuss the exclusion and its effect on the family's life.

**Overall, an incredible outcome was achieved for the family.**

<sup>2</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) [Overview of responses to the Experience of First Nations people with disability in Australia Issues paper](#)

<sup>3</sup> Deloitte (2023) *Research report. Options to improve service availability and accessibility for First Nations people with disability.*

<sup>4</sup> First Peoples Disability Network Australia (2018) [Ten Priorities to address disability inequity](#). (FPDN)

<sup>5</sup> Appendix 1 includes a full description of The Benevolent Society & Institute for Urban Indigenous Health Partnership including Grandmother's full story.

engaging with the Early Childhood Approach from below the population level to significantly above<sup>6</sup>.

## What would it take to expand this model?

**Funding:** The investment in time and effort to build genuine partnerships needs funding certainty. Once partnerships are established there is a much higher chance they can be sustained without additional funding. Some options for funding are:

- project funds with sufficient time allocated to create partnerships for access,
- incentive payments for providers who successfully achieve partnerships, and
- building room for partnerships in either block funding or unit prices – with accountability to ensure they are genuine and being delivered.

The UIIH partnership was established with funds available under the ECA block funded-style approach. Having separate funding for innovation was crucial to the partnership's success.

TBS has not been able to create partnerships of this quality as an NDIS provider. There are insufficient margins in the core hourly rates to fund innovation. Attempting to fund innovation through hourly rates creates an incentive for providers to capture the benefits of innovation within their own organisations, rather than sharing improvement options broadly with the market for the benefit of all people with disability.

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**Recommendation 1.1** – The creation of more partnerships between ACCOs and disability providers.

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**Workforce:** This partnership works because UIIH is the lead – they are the recognised authority. The Benevolent Society's role is to support and provide a seamless pathway in the application and planning process for NDIS services. The partnership's long-term ambition is to build the workforce within ACCOs so they can deliver more services independently. This shift is well progressed in other sectors such as primary health care and children's services and could be built on in disability.

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**Recommendation 1.2** – Funding to increase ACCOs' capacity to independently provide disability services as needed.

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## How does it measure against the fundamental NDIS principles?

**Choice and Control:** The partnership provides First Nations families with a culturally safe and appropriate service option, allowing for a better experience, less confusion and reduced stress. Maintaining relationships across each child's life trajectory through the embedded partnership ensures control stays with the participant. For example, each family can maintain the same key contact for supports either within their Aboriginal Medical Service or the Benevolent Society's Early Childhood Approach. Through this key relationship, families are also supported to access other Government and community services to ensure that wrap-around services can be provided where there are additional areas of need.

**Reasonable and Necessary:** By building a connector between supports and services, the need for families to relive or retell their stories is reduced. This soft entry to engagement is a strength of the partnership. Streamlining access through (informed consent) information sharing protocols between organisations assists with both engagement and retention of families. By considering cultural appropriateness at each step of the application process, families in the region are more comfortable accessing and engaging with services. Through community outreach programs such as local caravan park BBQ's, First Nations playgroups, and events in the community, clients have access to the most appropriate support more quickly (whether that is outside or inside the Scheme).

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**Recommendation 1.3** – Analysis of NDIA data on access for First Nations people so partnership projects can be commissioned in regions where they are most needed.

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<sup>6</sup> For example: 1,144 of 11,777 or 9.7% of access decisions in our three regions are represented by children who are Aboriginal and or Torres Strait Islander, this is significantly above the population level of Aboriginal and Torres Strait Islander people in our three regions of: Caboolture/Strathpine 3.9%; Brisbane 1.8% and; Logan/Beenleigh 4.2%.





## 2. Responding to Developmental Delay

The focus of supports for young children experiencing developmental delay (pre-diagnosis) should be on functional improvement, within an outcomes-based framework. The success of early intervention for children with developmental delays is linked more to parental responsiveness than service intensity<sup>7</sup>. Parent-child relationships form the foundation of early child development<sup>8</sup>, yet therapy for children with disability is often delivered separately from the family. A different approach is needed, built on the evidence that interventions are more effective when social elements and family collaborations are included.

The Benevolent Society recommends disability reforms include a commitment to create client pathways for children that emphasise their potential to make functional gain through high quality, evidence-based services, particularly for children with developmental delay. If effective these pathways should improve outcomes for individuals and reduce pressure on the Scheme.

### A Family-Focused Solution

More children with developmental delay than expected have entered the Scheme since June 2022<sup>9</sup>. For parents, who are understandably concerned about their child's development, the NDIS has provided service options at an unprecedented level. The system has also created incentives that drive individuals into plans without necessarily addressing developmental delay. The client experience for parents and children needs to shift to focus on the potential that children can achieve through evidence-based services. That will include the early identification of developmental delay, followed quickly with easy access to evidence-based programs of support that wrap-around children and their families.

The early intervention offered through *The Benevolent Society's Parent-Child Relationally Informed Early Intervention (PCRI-EI) program*<sup>10</sup> allows time for children with developmental delay to catch-up on their milestones, without an immediate expectation they will enter the Scheme. The program supports child development by actively working to strengthen the parent-child relationship and thereby optimise development and facilitate functional gains for children showing signs of

### Tag's Story<sup>8</sup>

Tag is 3 years old. He lives with his Mum (Rita) and Dad (Troy) who are expecting another baby. Tag attends a local childcare centre two days a week where he struggles to interact and make friends. Six months ago, Tag's parents started to worry about his language, play, emotional regulation, and gross motor skills.

A functional assessment showed Tag was presenting with developmental concerns. The family was enrolled into Early Supports through the Early Childhood Approach, with Sammy assigned as their key worker.

At the first meeting Rita's biggest concerns are Tag's toileting and ability to play confidently with others at childcare. Sammy explains this program actively involves parents in sessions - with positive parent-child interactions the foundation for goals. Together Sammy and Rita work on strengthening Rita and Tag's interactions as a foundation to help Tag's social play, speech and language and acceptance of changes. Sammy videos a few minutes of Rita and Tag's play and they review this together to see how Tag develops best.

Rita quickly realises Tag's engagement dramatically increased when she waits instead of jumping to action. At a follow up session Rita expresses that while not asking questions was hard, the results are undeniable Rita and had even been noticed by Troy and the rest of the family, who were now also engaged and trying to wait more.

Over time the improvements continue, with Tag's daycare advising Tag is more socially confident, playing and taking turns with other children.

<sup>7</sup> Atkins-Burnett & Allen-Mearns, 2000; Innocenti, Roggman, & Cook, 2013; Karaaslan, Dikey, & Mahoney, 2013

<sup>8</sup> Edelman (2004) *A Relationship-Based Approach to Early Intervention*. Originally published in Resources and Connections July-September, 2004. Vol 3, No 2

<sup>9</sup> NDIS Review (2023) NDIS Quarterly Report to Disability Ministers. pg 7

<sup>10</sup> Appendix 2 includes a full description of Parent-Child Relationally Informed Early Intervention (PCRI-EI) program including Tag's full story.



developmental delay. The program is inclusive, so all families regardless of vulnerabilities (such as trauma) benefit from the family focused therapy.

## What would it take to expand this model?

**Funding:** To expand delivery of this model beyond its current application in the Early Childhood Approach, client pathways that incorporate a fully funded ‘course’ of therapy, rather than ‘a number of hours’, would be needed. A course of therapy could be provided as part of a bundle of services. This will require the NDIS and providers’ actively talking to clients and their families about the evidence – what and how different therapies work best to achieve outcomes. However, the additional training required to skill up allied health professionals to work in this model would be challenging, if not impossible, for employers to provide in an hourly fee payment structure. More broadly, language at all touchpoints in the NDIS client journey needs to emphasise a client’s potential more consistently.

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**Recommendation 2.1** – Consideration of funding therapy and behaviour support as a bundle, not individual hours, when it is being provided to achieve functional gain. Bundling may assist participants to choose and providers to deliver services based on their effectiveness rather than hours of service. The size of bundles could be linked to evidence about the amount of therapy that would be expected to achieve potential gains.

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**Workforce:** A practitioner’s ability to engage parents, co-create family goals, and sensitively encourage parental reflection and responsiveness sit at the core of this program. This needs skilled early childhood educators and allied health professionals specifically trained in delivering a relationally informed model of care. Its success is built on practitioner confidence to encourage and train parents to become attuned and responsive to their child’s ways of communicating. The development of an accredited workforce of skilled practitioners would assist to support expansion of the model.

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**Recommendation 2.2** – Funding to train a sufficiently sized workforce with a high degree of competency in relationally informed model of care.

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## How does it measure against the fundamental NDIS principles?

**Choice and Control:** The availability of a relationship-based therapy model, potentially within a bundle of services, expands and provides better quality choices for the families of children with developmental delay. Ideally funding models would allow multiple providers to develop expertise in evidence-based models, offering an expansion of choice in services.

**Reasonable and Necessary:** The potential for relationship-based early intervention to improve functional outcomes, potentially to the point that children experiencing developmental delay never need to enter the NDIS as participants, points to its value as a reasonable intervention. Some people, like Tag and his family, may only need one course of intervention, others may need two. For other people, it may be reasonable and necessary to move to more intensive service offerings as a participant within the Scheme.

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**Recommendation 2.3** – Analysis of NDIA data to understand the range of therapy hours being used by different groups of children with disability, such as children with developmental delay, and any relationship that can be found with goal attainment and long-term use of the NDIS.

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## 3. Supporting Clients with Complex Needs

Participants with complex needs often live at multiple intersections of need - requiring sophisticated choices with room to adapt. Complex cases benefit from a mix of approaches, yet individual supports are not appropriate or able to address each type of support need<sup>11</sup>. Approaches need to be flexible and collaborative, recognising that people with disability are much more likely to experience trauma and/or violence in their lifetime than non-disabled peers<sup>12,13</sup>.

**The Benevolent Society recommends disability reforms include the establishment of market settings that support multidisciplinary coordinated responses for clients with high needs and that create and maintain an adequate pool of suitably qualified practitioners.**

### A Multidisciplinary Solution

A long-standing problem under the NDIS has been to find ways to support participants with complex needs. Every day our staff work collaboratively to provide the best multidisciplinary support possible –bespoke to each client.

This approach has been detailed in a case study on *Dane, a school-aged child with complex support needs receiving therapy supports*<sup>14</sup>. Dane requires high quality, well-coordinated and trauma-informed supports to maximise his functional gains. Unconnected therapy services for behaviour support, speech and occupational therapy are unlikely to be able to keep Dane and the totality of his needs, in the context of his family life with Stacey, at the centre of their focus. The option of easily accessible, well informed, and up-to-date case management or key worker support needs to be available to support Dane and Stacey. Further, the people working with Dane need to be highly skilled, well trained, and able to exercise judgement about the best way to support Dane’s progress over time.

### What would it take to expand this model?

**Funding:** Complex needs require calibrated case management by experienced practitioners with the skills to use judgement and initiative. ‘Off the shelf’ solutions will not suffice. Current plans are not sufficient to provide the coordination and high-quality

### Dane’s Story<sup>14</sup>

8-year-old Dane has a primary disability of intellectual disability and secondary diagnosis of autism/ASD. He communicates through body movements and vocalisations. Dane does not have a functional communication system and engages in behaviours of concern, including spitting towards people and objects.

**Stacey, Dane’s mum has expressed a history of domestic and family violence.** The Benevolent Society team links Stacey and Dane into additional supports to develop a holistic approach. Dane’s Behaviour Support Practitioner (BSP) acts as the keyworker so Dane, Stacey, and their support network have a single point of contact.

**Dane’s overarching NDIS goal is to maximise his participation in home, school, and community settings.** To meet this, Dane and his family receive supports including speech pathology, occupational therapy, and behaviour support. The wrap-around support for Dane is delivered in collaboration with his family, educators, and other formal and informal supports.

**The BSP liaises with the speech pathologist and occupational therapist to address goals collaboratively.** The communication goal requires a high level of engagement and collaboration with Dane’s school. Working in partnership with external agencies enables a generalisation of outcomes across settings, ensuring a holistic, wrap-around approach to Dane’s supports.

**While ongoing, the approaches taken successfully maximise Dane’s participation, self-efficacy, and sense of achievement.**

<sup>11</sup> Productivity Commission (2011). *Disability Care and Support*. Report no. 54, Canberra.

<sup>12</sup> McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 34(4): 927-949. <https://doi.org/10.1111/jar.12872>

<sup>13</sup> Purpose at Work (2022). *Right on Board: Governing and Managing for Human Rights, Quality and Safeguarding: A capacity building program for disability service providers*, v.2 – January 2022. Franklin, ACT: Purpose at Work.

<sup>14</sup> Appendix 3 includes a full description of The Benevolent Society’s multidisciplinary best practice as a case study, including Dane’s full story.

care that is required. It is difficult to find room in current plans to fund staff participation in case conferencing. Currently hourly rates do not have sufficient margin to do this work in 'unbillable' time. Bundled or differential hourly rates should be considered as options for complex supports. Differential prices for complex supports could be accompanied by an expectation of practitioner accreditation, demonstrating their ability to deliver high quality services.

**Workforce:** The availability of suitably skilled practitioners to undertake this work is essential. Experienced practitioners able to exercise judgement and initiative are best placed to offer effective and efficient services. Practitioners early in their career or new to working with people with disability require higher levels of support and supervision, particularly when supporting clients who have complex needs. This requires a structured pipeline for allied health and behaviour support workers, joining undergraduate theoretical knowledge with practical on-the-job skills development, and continuing over a whole career. Building this level of proficiency starts by accepting new workers will have a lower utilisation in the first year of employment. Training in disability support is also necessary - this is a speciality area that requires ongoing targeted skill development to maintain quality.

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**Recommendation 3.1** - Immediate priority focus on models that fund providers' role in workforce development and create a structured pipeline for allied health and behaviour support workers.

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## How does it measure against the fundamental NDIS principles?

**Choice and Control:** People with complex disabilities could be better supported to exercise more meaningful choice if they could choose between a smaller number of high-quality providers rather than a large number of mediocre or low-quality providers. To achieve this, enough high-quality providers would need to be present in the market, and the well recognised problem of information asymmetry within the NDIS will need to be addressed. The Review's proposal to make recommendations about Scheme data and integrity would assist to address this challenge. For example, easily accessible data about the availability of specialist accredited providers would be helpful.

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**Recommendation 3.2** - The creation of an accessible and easy to use mechanism so participants can assess the quality and specific expertise of possible therapy providers.

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**Reasonable and Necessary:** The NDIS Review has already indicated that outcomes measurement will be a focus of its recommendations. The Benevolent Society welcomes this approach. Measurement of functional improvement and pathways to understand potential further improvement would support effective services for people with complex disabilities. A highly skilled workforce able to deliver adaptive approaches as needs change over time will be necessary. This should be supported by an outcomes framework and funding approaches for people with complex disability who join the NDIS in childhood must be able to 'dial up and down' easily over a lifetime.

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**Recommendation 3.3** - A standard way to measure functional gain, co designed with participants, providers and academics.

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The needs of many people with disability will change over time, for example as a child grows and develops, however funding structures are not flexible enough to move with these changes. Our experience is that participants often seek to maintain large packages so therapy and supports are available to meet anticipated future changes. The recent trend to reduce the size of packages with unused hours, creates a perverse incentive to use all hours each year. This incentive could be changed through a mechanism that makes it easy for clients and families to increase support around predictable life events. For example, a pathway where families of children with significant disabilities are proactively contacted in the last year of primary school to offer plans assisting with the transition to high school. This may give families confidence to then reduce plan size at other times when therapy offers less value as they know appropriate services will be available over the long term.

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**Recommendation 3.4** - A mechanism that allows participants, particularly children, who stop or reduce therapy hours to easily restart services when they reach major transition points such as adolescence.

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Further, the identification of reasonable and necessary supports requires an evidence base to enable choice between a potential range of services on offer. The availability of authoritative and easy to use information about the evidence base for different therapy and behaviour approaches would assist people with disability and their families to choose effective services.

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**Recommendation 3.5** - Ways for participants, providers and researchers to collaborate on the use and development of evidence on the effectiveness of therapies and behaviour support.

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## 4. Soft Entry Points and the role of State and Territories

**For children at risk of exclusion and falling behind, their wellbeing and life outcomes improve when integrated, wraparound supports are available<sup>15</sup>.** Often the children and families who most need services are the ones more likely to miss out<sup>16</sup>. Integrated services can change this, by providing soft entry points into targeted, wraparound supports. Local solutions built on community networks and knowledge provide the best supports. State and Territory government funding for community-based support options helps connect people to the services they need.

**The Benevolent Society recommends disability reforms include State and Territory government contributions that create a network of locally available soft entry points for families, that integrate universal and targeted services, supports and therapies:** with increased investments into soft entry points, funding for co-located multidisciplinary teams that wrap around children and their families, and investment into nationally agreed childhood outcomes measures.

### An Integrated Solution

**In The Benevolent Society's experience the most successful integrated programs are designed and implemented with, and for, the community in which they operate.** Collaborating with other non-government service providers, ACCOs and the relevant State or Territory Government can create even more benefits for clients. This is the collaborative approach taken in *The Benevolent Society's Early Years Places<sup>17</sup>*, funded by the Queensland government. Our Early Years Places create a bridge between informal and formal assistance so staff can provide an extended suite of services in a welcoming and familiar 'one-stop shop' setting.

**The soft entry offered through Early Years Places means children walk through the doors to a range of services that can be tailored for each family in a non-stigmatising and family friendly way.** Their strength comes from an ability to engage vulnerable families, identify developmental and family risks early, and then retain families long enough for supports to have impact. Early research by our partners at Social Outcomes shows

### Sarah's Story<sup>17</sup>

30-year-old Sarah is in a de facto relationship and has a daughter, Michelle (3 years old) and a son, Jack (5 years old). They live in social housing. Both the children and their father identify as First Nations. Jack and Michelle are both experiencing developmental delays. Sarah left school in Year 9 and does not currently have a paying job. She has a long history of domestic family violence in the home. Sarah spends most of her time at home and is very cautious of people she doesn't know.

**Sarah found out about The Benevolent Society Early Years Program (EYP) when her doctor at the local Aboriginal and Torres Strait Islander health service suggested she make contact.** After calling the service, Sarah was invited to bring Michelle and Jack to the Explorers Playgroup, specifically designed for children experiencing developmental delays. Sarah feels great relief talking about her parenting experiences with parents going through similar challenges.

**Sarah quickly realises the staff are an amazing resource— with an occupational therapist, a speech pathologist and a child and family practitioner all under the same roof.** In addition to regular staff supervision, the Team Leader in charge of Sarah's case actively engages Sarah about how well the interventions are working. And the support continues, including help seeking affordable housing and finding a school that can best support Michelle's needs.

**Over time, Sarah and her children experience secure housing, improved community connection and Michelle successfully transitions to school.**

<sup>15</sup> Molloy C, O'Connor M, Guo S, et al. (2019) Potential of 'stacking early childhood interventions to reduce inequalities in learning outcomes. J Epidemiol Community Health

<sup>16</sup> Fox, S., Southwell, A., Stafford, N., Goodhue, R., Jackson, D. and Smith, C. (2015). *Better Systems, Better Chances: A Review of Research and Practice for Prevention and Early Intervention*. Australian Research Alliance for Children and Youth (ARACY). Canberra

<sup>17</sup> Appendix 4 includes a full description of The Benevolent Society's Early Years Places, including Sarah's full story.

through a breakeven analysis that it only takes one child in a cohort to ‘do well’ for the benefits to exceed the costs<sup>18</sup> – this is a solution ready to be scaled.

## What would it take to expand this model?

**Funding:** Funding must be sufficient to maintain high quality services through a rigorous quality assurance framework, and flexible enough to ensure families can ‘dip in’ and ‘dip out’ of services based on need. Funders and program designers would need to take on a social entrepreneurial mindset, engage proactively in service design with local providers and have the authority to resource and broker integrated supports with accredited service providers and local mainstream services. Sophisticated models of practice would need to be supported - this may mean co-commissioning of shared outcomes with local health, education and social service funders.

Funding levels would need to be sufficient to deliver equal access to services across Australia, particularly in lower socio-economic communities. This could be part of State and Territory governments’ role in providing and funding social infrastructure. If this approach were delivered at scale, it would be a material contribution by States and Territories to disability services.

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**Recommendation 4.1** – Increased investment to establish new (and expand current) local soft entry points, particularly in lower income communities.

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**Workforce:** The recently released report of the South Australian Royal Commission into Early Childhood Education and Care supports the expansion of integrated child and family hubs. The Report states, “The work of the early childhood workforce in connecting families to the supports they need is often referred to as ‘the glue’. The [Royal Commission’s] Interim Report found this work is underfunded and under-recognised. Creating ‘the glue’ is challenging given the involvement of different layers of government and non-government players in early childhood services.”<sup>19</sup>

The ability to create and sustain ‘the glue’ also depends on having a highly skilled, dedicated, innovative and practically minded workforce. Early Years Places work because they employ multidisciplinary early childhood and allied health staff across a range of universal and targeted early child development and support services. In addition, service staff also need to be aware of and capable of building and maintaining solid links and collaborative relationships with other local community service providers.

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**Recommendation 4.2** – Funding to co-locate multidisciplinary teams that wrap around children and their families.

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## How does it measure against the fundamental NDIS principles?

**Choice and Control:** Where earlier and better integrated supports are available for at risk children and their families, regardless of background, circumstances, or location, better outcomes can flow. Community based approaches built on principles of proportionate or targeted universalism, with multiple soft entry points, provide the most successful model, particularly for vulnerable families. Contacting a service for support can be daunting, and getting this right is vital to creating an environment of trust and engagement. The availability of soft entry points in education settings, childcare centres, workplaces, sports and recreation settings, media, health, and community services supports choice and control.

**Reasonable and Necessary:** Every child deserves the best possible start in life. For children at risk of exclusion and falling behind, it is both reasonable and necessary to develop effective, reliable pathways to support that avoids these risks. Early interventions that can avert a crisis later in life are worth the investment, as The Benevolent Society’s early measurement work with Social Outcomes demonstrates. The benefits of early intervention flow from children and families at the core, and onto the wider community.

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**Recommendation 4.3** – Investment in accountability for improved childhood outcomes by establishing, capturing, and publishing a set of nationally agreed measures.

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<sup>18</sup> Social Outcomes (2022). *Impact Report: TBS Early Years Places in Queensland*.

<sup>19</sup> Government of South Australia (2023) *Royal Commission into Childhood Education & Care. Interim Report*. 2<sup>nd</sup> Edition p63



# Appendix 1: The Benevolent Society and Institute for Urban Indigenous Health Partnership

In Southeast Queensland, The Benevolent Society has partnered with the Institute for Urban Indigenous Health (UIIH) to collaboratively deliver the Early Childhood Approach. First Nations families are consistently underrepresented in the design and delivery of services. The partnership works to change this - reducing barriers to services and cultivating trust within communities through a culturally meaningful and client-centred approach.

## Context

The Benevolent Society has been the NDIS Early Childhood Partner in the Community since 2018, delivering the Early Childhood Approach for the Brisbane, Beenleigh-Redlands, Caboolture - Strathpine regions. Since 2020, this work has been extended through an innovative partnership with the Institute for Urban Indigenous Health (UIIH). Evidence shows that the single biggest factor in improving health and social outcomes for Indigenous people is self-determination<sup>20</sup>. When First Nations people have control of the design and delivery of services in their communities, it is more likely these services will be culturally safe and responsive.

The significance of First Nations leadership has been evident in The Benevolent Society/IUIH partnership. The first of its kind in Australia, the partnership has increased the impact of services in the region by ensuring First Nations families have access to culturally appropriate supports. Over the last three years this partnership has lifted the number of First Nations families engaging with the Early Childhood Approach from below the population level to significantly above<sup>21</sup>. The rate of NDIS plans being utilised by First Nations families to support their child's development through the Early Childhood Approach has also continued to grow, in large part due to the work maintaining relationships across each child's life trajectory - including across both UIIH and The Benevolent Society's services through the embedded partnership. For example, each family can maintain the same key contact for supports both within their Aboriginal Medical Service and The Benevolent Society's Early Childhood approach. Through this key relationship, families are also supported to access other government and community services to ensure that wrap-around services can be provided where there are additional areas of need.

## Why this partnership works

### **It ensures self-determination and actively works to close-the-gap.**

Services that have the greatest impact for First Nations families are led and designed by the First Nations community. This program works because UIIH is the lead – they are the recognised authority, while The Benevolent Society's role is to support and provide a seamless pathway in the application and planning process for NDIS services. The model has been set up to ensure service delivery is led by our First Nations community, with The Benevolent Society funding a leadership position that is employed and sits within UIIH. This position leads all decisions on service design for First Nations families.

### **It takes a culturally meaningful and client-centred approach.**

The partnership ensures First Nations families are engaged through culturally appropriate processes, allowing for a better experience, less confusion and reduced stress. This has included connecting families in community outreach programs such as local caravan park BBQs, First Nations playgroups, and events in the community. By considering the cultural appropriateness within each step of the application process, families in the region are more comfortable accessing and engaging with Early Childhood Approach services.

### **It leverages relationships with existing community leaders, practitioners, and professionals.**

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<sup>20</sup> M Bamblett & P Lewis, 'Detoxifying the child and family welfare system for Australian Indigenous peoples: Self-determination, rights and culture as the critical tools', *The First Peoples Child & Family Review*, vol. 3, no. 3, 2007, pp. 43–56

<sup>21</sup> For example: 1,144 of 11,777 or 9.7% of access decisions in our three regions are represented by children who are Aboriginal and or Torres Strait Islander, this is significantly above the population level of Aboriginal and Torres Strait Islander people in our three regions of: Caboolture/Strathpine 3.9%; Brisbane 1.8% and; Logan/Beenleigh 4.2%.



Equitable access to supports for First Nations families is a significant challenge for Early Childhood Approach services. A plan by itself is not enough. It needs the right facilitation – led and designed by the First Nations community. This partnership reduces the barriers to engagement by working within an existing environment of trust within the community. By working as a connector between supports and services the need for families to relive or retell their stories is reduced. This soft entry to engagement is a strength of the partnership. Streamlining access through (informed consent) information sharing protocols between organisations assists with both engagement and retention of families.

## Next Steps

The success of this partnership has seen the partnership grow from funding one position to now funding four positions. These positions include a leadership level position as well as three ‘navigation partner’ positions (one for each funded region).

Our work in this space has seen the NDIA include the stipulation in all Community Partner Contracts, that Partners in the Community *must have established partnerships with their local Aboriginal Controlled Community Organisation in delivering their contracted requirements*. The Benevolent Society believes that this is a step in the right direction - but continues to advocate that services designed for First Nations families should be led by ACCOs that work in partnership with like-minded NGOs to ensure that services are accessible and equitable for all.

## Grandmother’s Story \*<sup>22</sup>

**Grandmother has been caring for her granddaughter (5 years) from the age of 3 months in a kinship care arrangement.** Both grandmother and granddaughter identify as First Nations people. The granddaughter has developmental delays that are impacting on her grandmother’s ability to continue to care for her granddaughter.

**The family was overwhelmed.** When the IUIH/TBS ECA Partnership team visit, they identify through yarning that while the NDIS was the family’s primary concern, additional concerns exist around schooling, mental health, and carer fatigue. The family are becoming concerned about their ability to care for their granddaughter and the grandparents’ relationship is being particularly affected by the stress.

**The grandparents were able to access free IUIH supports due to the partnership and warm referral.** They were linked in with a paediatrician and allied health professionals after completing a 715-health check with the GP. This flowed to referrals for further supports and allowed Grandmother to gain access to the NDIS through the partnership.

**Moving forward the partnership team connected Grandmother to external support that assisted with the granddaughters’ schooling concerns.** One key area was school exclusion, as the school required the granddaughter to be collected by 12 o’clock every day. During the planning meeting Grandmother disclosed the school had even sent a letter advising her granddaughter would no longer be welcome unless her emotional development improved. Grandmother had been led to believe the 12pm exclusion was normal - that the school was helping. The partnerships team advised Grandmother the school had a responsibility to be inclusive – so should be focused on building capacity so teachers were able to properly support the granddaughter. Another First Nations service was brought into advocate. They organised a community Elder to accompany Grandmother to the school and discuss the exclusion and its effect on the family’s life.

**Overall, it was an incredible outcome for the family.** IUIH and The Benevolent Society worked together as a team and together connected the family to even more services. So much support was wrapped around Grandmother - she is positive now that she can continue to care for her young granddaughter.

<sup>22</sup> Grandmother’s Story was told as part of digital story for The Benevolent Society and IUIH with consent to share given by the family on the 1<sup>st</sup> of December 2021.

## Appendix 2: The Benevolent Society's Family-Centred Early Support

The Benevolent Society's family-centred Early Supports program (PCRI-EI program) sits within the Early Childhood Approach. Outcomes for children with developmental delays improve when the parent-child relationship is sensitive and attuned. The program recognises this, supporting child development by actively working to strengthen the parent-child relationship and therefore optimise development and facilitate functional gains.

### Context

The Benevolent Society has been delivering innovative early childhood and family support services for ECA across Queensland for over five years. The PCRI-EI program is our latest practice initiative supporting approximately 550 families from a diverse range of cultural and social backgrounds in the Brisbane region. The PCRI-EI program focuses on strengthening the responsiveness of parents to their child who is experiencing developmental delays as the foundation for functional and family gains. This positive parent-child relationship becomes the conduit for the child, family and therapist to collaboratively explore new skills and target goal-orientated interventions more effectively.

### Why being family-centred works

**It aligns with the current evidence base on what works best for children with developmental delays.**

The success of early intervention for children with developmental delays is linked more to parental responsiveness than service intensity<sup>23</sup>. Parent-child relationships form the foundation of early child development<sup>24</sup>, yet therapy for children with disability is often delivered separately from the family. The PCRI-EI program is both consistent with and builds on evidence that shows interventions are more effective when social elements and family collaborations are included<sup>25</sup>.

**It values, strengthens and then leverages the role the parents play in their children's lives.**

The PCRI-EI program starts by working with parents to build their capacity to navigate what is often a complex parenting environment<sup>26</sup>. The practitioner focuses on strengthening positive parent-child interactions of warmth, sensitivity, responsiveness, and adaption to the child's needs<sup>27</sup>. Through this process parents become more adept at reading and responding to the unique needs of their child. This enables the child to trust they will be supported in their exploration, persistence at and mastery of new tasks. This reading of cues and adaptation of responses moment to moment, creates a strong foundation for achieving the functional goals parents have for their child. Ultimately the parent feels more empowered to support their child's development and there is less reliance placed on the therapist's role in achieving this.

**It focuses on child outcomes rather than therapeutic intensity.**

In this program the parent-child relationship becomes the foundation of the intervention as well as the method through which the intervention is delivered. This is done through a phased approach where goals are co-created with families taking a long-term view and beginning with the question "*what are your hopes for your child when they are 25?*". From there, the therapist and caregiver discuss how to orient their short-term goals towards those hopes in light of what was learned during the assessment process. This sets the therapy as working towards a desired outcome (appetitive control), rather than trying to avoid a negative (aversive control) one, which is known to increase parental engagement and optimise family outcomes.

<sup>23</sup> Atkins-Burnett & Allen-Meares, 2000; Innocenti, Roggman, & Cook, 2013; Karaaslan, Dikey, & Mahoney, 2013

<sup>24</sup> [https://cacenter-ecmh.org/wp/wp-content/uploads/2012/03/relationship\\_based\\_approach.pdf](https://cacenter-ecmh.org/wp/wp-content/uploads/2012/03/relationship_based_approach.pdf)

<sup>25</sup> Barfoot, Meredith, Ziviani, & Whittingham, 2017; Case-Smith, Clark, and Schlabach, 2013) (p. 421) Oono, Honey, and McConnachie (2013); van Zeijl et al., 2006; Dirks, Blauw-Hospers, Hulshof, & Hadders-Algra, 2011

<sup>26</sup> Maclean M J., Sims S, Bower C, Leonard H, Stanley FJ, O'Donnell M; (2017) *Maltreatment Risk Among Children With Disabilities*

<sup>27</sup> John Callanan, Tania Signal & Tina McAdie (2023) Involving Parents in Early Intervention: Therapists' Experience of the Parent-Child Relationally Informed-Early Intervention (PCRI-EI) Model of Practice, *International Journal of Disability, Development and Education*, 70:5, 674-687, DOI: [10.1080/1034912X.2021.1910933](https://doi.org/10.1080/1034912X.2021.1910933); Barfoot et al., 2023.

Practitioners integrate families into therapy through a practical application of the PAIR model (see Figure 1).

The strength of this program comes from its ability to engage parents, co-create family goals, and sensitively encourage parental reflection and responsiveness. Strengthening parent-child interactions occurs through co-created strength-based goals, family observation, and video reviews that encourage parental reflection, cue reading and reframing of behaviours around context rather than diagnosis.

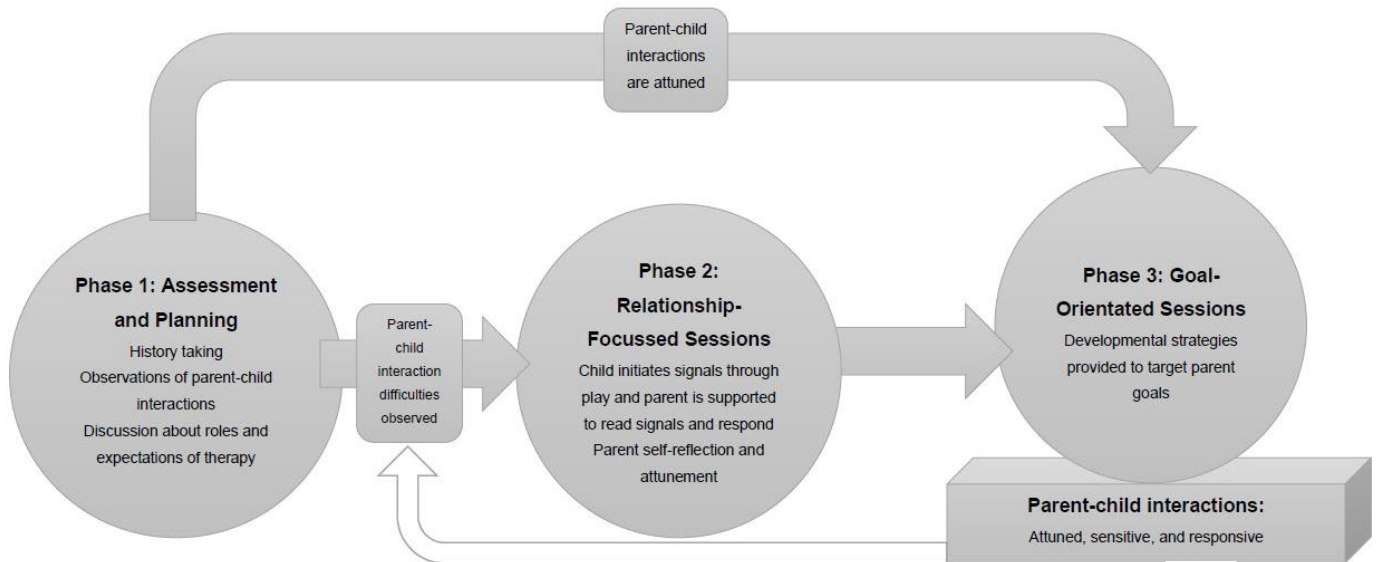


Figure 1: Proposed Process Model: A Phased Approach to Incorporating a Relationship-focus (PAIR) <sup>25</sup>

## A Phased Approach to Child Development

The way in which goals are created and approached are central to the PCRI-EI intervention. Co-created with a long-term view, the early phases of therapy in particular are focused on facilitating the parent's active involvement in their child's particular developmental needs.

### Phase 1 - Setting the Foundations

Observation, narration, waiting, and following the child's ideas set the foundation. The first objective is to help parents observe and notice what their child is interested in and doing without rushing in to help. Practitioners help the parents take the perspective of the child and what it might feel like to them if the parent is taking control or jumping in to help too quickly.

### Phase 2 - Reflective capacity, cue reading, and active imitation

This includes encouraging parents to read and respond to all of the different ways that their children provide cues. Video review is used here. A major question for caregivers in this phase is "What do you think they are telling us right now? What might be underneath that?"

### Phase 3 - Affect regulation of parent and child

This involves helping parents help their child manage a range of emotions they may experience in different contexts (e.g., frustration with a task or interaction), and also helping parents tune in to their own emotional responses to their child's behaviours (which may include grief, loss, and confusion). This may look like having parents say observations of the child's feelings as they come up (positive and negative).

### Phase 4 - Reframing behaviour and appreciating contextual issues

In this phase, we are helping parents shift from thinking about a child's behaviour (or things they say) from a "why are they doing this?" perspective to "what are they telling me about their experience right now?" Additionally, we are helping parents think in terms of what is "helpful" and "unhelpful" or "worked" and "didn't work" in a given

context, rather than “right or wrong” responses. This helps parents think about behaviour in context, rather than as a result of the child’s disposition or diagnosis.

### Phase 5 - Integration, relapse prevention, and generalization

In the final phases work turns towards integrating everything learned so that they rely more on what they know about their child and their experiences rather than worries about diagnostic descriptors or potential challenges.

## Next Steps

We know relationally informed early intervention works.

The next step must be measuring family outcomes systematically.

The Early Supports program have partnered with The University of Queensland to commence a research project with Honours students through the School of Occupational Therapy. These research projects will evaluate practitioner implementation of the PCRI-EI program, and functional and family gains.



## Tag’s Story\*<sup>29</sup>

**Tag is 3 years old.** He lives with his Mum (Rita) and Dad (Troy) who are expecting another baby. Tag attends a local childcare centre two days a week where he struggles to interact and make friends. Six months ago, Tag’s parents started to worry about his language, play, emotional regulation, and gross motor skills.

**Rita called The Benevolent Society to see if he was eligible for support.** A functional assessment showed Tag was presenting with developmental concerns, so the family was enrolled into Early Supports through the Early Childhood Approach with Sammy assigned as their key worker.

**At the first meeting Rita’s biggest concerns are Tag’s toileting and ability to play confidently with others at childcare.** Together Sammy and Rita plan to move all nappy changes into the toilet, starting with Rita emptying Tag’s nappy into the toilet and involving Tag in flushing the toilet. They talk about books, songs and video clips to support Tag’s understanding of toileting, and ways to help Tag feel safer with routine changes and trusting others by practicing this in play. Sammy explains these skills can be strengthened by following Tag’s play ideas and putting words to what Tag is doing and feeling.

**Rita is told how this program actively involves parents in sessions - with positive parent-child interactions used as the foundation for goals.** Sammy explains that strengthening Rita and Tag’s interactions can then help Tag’s social play, speech and language and acceptance of changes. A learning pyramid is used to help show how this links to Rita’s specific goals for Tag. Sammy also videos a few minutes of Rita and Tag’s play – this is reviewed by Rita and Sammy to see how Tag develops best. Rita feels relieved, saying this feels like a good fit with her parenting values. Together Sammy and Rita write a summary about what worked well in the first session. Rita is keen to practice at home, saying “*before when I was asking him questions, he didn’t actually respond back. When I waited today and said statements of what he was doing, he actually listened and responded!*”. Rita aims to do 5-10 minutes of this structured play most days until the next session.

**Rita quickly realises Tag’s engagement dramatically increased when she was able to wait instead of jumping to action.** At a follow up session Rita expressed that while not asking questions was hard, the results were undeniable. Tag had started toileting into the bathroom and was even becoming involved in flushing the toilet. She said Troy and other family members at home had noticed and were now engaged in trying to wait more and to put words to Tag’s play. Rita felt great relief that the family was more connected and relaxed when playing with Tag.

**Over time the improvements continue, with Tag’s daycare advising Tag is more socially confident, playing and taking turns with other children.** At the point of transition from Early Supports, Rita reports confidence in her strategies to continue working with Tag, because of the way Sammy helped strengthen her interactions in play with Tag.

<sup>29</sup>Tag’s Story was told to Dr Jacqueline Barfoot and The Benevolent Society with consent to share given by the family on the 4<sup>th</sup> of May 2023.

## Appendix 3: ‘What Good Looks Like’ for a school-aged child with complex support needs receiving therapy supports

The Benevolent Society has significant experience working with people with a disability across the lifespan, in a range of service settings. Every day our staff work collaboratively to provide the best multidisciplinary support possible. There is no one-size fits all solution. This is why we advocate for approaches to be flexible and collaborative - focused on ensuring all clients have the wrap-around support they want and need.

**Dane is an eight-year-old boy who attends a support class in a mainstream public school.** Dane has had an individualised NDIS Plan since age six. Dane has a primary disability of intellectual disability and secondary diagnosis of autism/ASD. Dane communicates through his body movements and vocalisations. Dane does not have a functional communication system and engages in behaviours of concern, including spitting towards people and objects. Dane’s therapy team are part of Dane’s formal support system to understand his behaviours and help him actively participate in his daily routines.

**Dane has an overarching NDIS goal of maximising his participation in home, school, and community settings.** To meet this goal, Dane and his family receive supports from The Benevolent Society, which is an NDIS-registered provider of allied health and behaviour supports. Dane’s supports include speech pathology, occupational therapy, and behaviour support and, whilst each discipline has a shared goal of participation, each brings discipline-specific knowledge to the approach.

Dane’s therapy goals include:

- For Dane to have access to a robust communication system for aided language stimulation;
- For Dane to have sensory opportunities with functional equivalence for his spitting behaviours; and
- For Dane to experience predictable, non-restrictive, and non-contingent engagement from his family, educators, and support people.

**The wrap-around support provided to Dane is delivered in collaboration with his family, educators, and other formal and informal support networks.** Wrap-around supports are particularly important when we consider the evidence, which tells us:

- People with intellectual disability are more likely to experience trauma than the general population<sup>30</sup>
- People with cognitive disability are 2.4 times more likely to experience violence in their lifetime than non-disabled peers;<sup>31</sup> and
- Mothers of children with disability are two times more likely to be hospitalised due to domestic and family violence than mothers of children without disability.<sup>32</sup>

**Dane’s mum, Stacey is a Wiradjuri woman living in regional NSW.** Stacey is separated from Dane’s father but maintains a close relationship with Dane’s paternal grandfather. Stacey has expressed that there is a history of domestic and family violence. Building Stacey’s network of informal supports helps build Stacey’s capacity and resilience, and, in turn, supports Dane’s inclusion in community. Organisations like The Benevolent Society, that have expertise across disability and child and family sectors, can leverage their expertise in child development, child protection, and family-centred practice to ensure a holistic approach. Culturally safe and culturally responsive approaches to engagement are paramount.

**Dane’s Behaviour Support Practitioner acts as the keyworker so that Dane, Stacey, and their support network have a single point of contact.** The keyworker works with Stacey to develop Dane’s support plan for therapy and behaviour support and helps Stacey prioritise their goals. These are:

<sup>30</sup> McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 34(4): 927-949. <https://doi.org/10.1111/jar.12872>

<sup>31</sup> Purpose at Work (2022). *Right on Board: Governing and Managing for Human Rights, Quality and Safeguarding: A capacity building program for disability service providers*, v.2 – January 2022. Franklin, ACT: Purpose at Work.

<sup>32</sup> Octoman, O., Hawkes, M., Lima, F., O’Donnell, M., Orr, C., Arney, F., Moore, T., Robinson, S., valentine, k., Marshall, A., Burton, J., & Brebner, C. (2022). The nature and extent of domestic and family violence exposure for children and young people with disability (Research report, 16/2022). ANROWS. [https://anrowsdev.wpenginepowered.com/wp-content/uploads/2022/09/RP.20.06-Robinson-RR1-Nature\\_Extent-DFV-YP-wDisability.2.pdf](https://anrowsdev.wpenginepowered.com/wp-content/uploads/2022/09/RP.20.06-Robinson-RR1-Nature_Extent-DFV-YP-wDisability.2.pdf)



- Helping Dane to stop spitting at people, as this behaviour is impacting on people's willingness to work with him; and
- Improving Dane's ability to communicate, as Stacey is worried this is a source of frustration for Dane.

**The Behaviour Support Practitioner liaises with the speech pathologist and occupational therapist to address these goals collaboratively.** The behaviour support practitioner also notes that Stacey uses a stroller when taking Dane out in the community, which is not required for mobility reasons. The practitioner provides education around why this would be considered a restrictive practice if used by Dane's educators or other support people. The practitioner chats with Stacey about how the use of the stroller could be gradually phased out as Dane develops his skills, including a reduction in spitting behaviours, and how this will positively impact Dane's participation and social inclusion.

**With regards to Stacey's goal to develop Dane's communication, the speech pathologist suggests Dane will benefit from a robust, visual language system.** The speech pathologist develops a core vocabulary board for Dane using Crescendo core vocabulary<sup>33</sup> and tailored fringe vocabulary that includes Dane's daily activities, familiar people, and special interests. The core board includes a cross-body strap with quick release mechanism, making it simple and safe to transport. The initial goal is for Dane to have consistent access to the core board, and progress towards this goal is regularly reviewed using a functional goal setting approach.<sup>34 35</sup> Table 1 shows how Dane's communication goal is developed over time.

**The communication goal requires a high level of engagement and collaboration with Dane's school.** Working in partnership with external agencies enables generalisation of outcomes across settings and ensures a holistic, wrap-around approach to Dane's supports. Dane's educators and Learning Support Officers help implement the core vocabulary approach in functional, learning activities and help to monitor Dane's progress over time.

**Having the communication board available before school was challenging for Stacey, so the focus shifted to implementing a visual schedule to help with the morning routine.** The visual schedule supports Dane in two ways:

- Dane has a visual prompt of what he is expected to do; and
- Dane experiences a predictable routine because the tasks are sequenced in the same order each morning.

**Dane's occupational therapist (OT) works with Stacey and Dane to understand their morning routine and develop a task analysis.** The task analysis breaks down each task into steps, so that Stacey can support Dane using 'backward chaining' technique. With backward chaining, Dane is supported to complete the last step of the task, then the next-to-last step, and so on. This approach helps to maximise Dane's participation, self-efficacy, and sense of achievement.<sup>36</sup>

**The OT and the behaviour support practitioner work together to understand the function of Dane's spitting behaviours and develop appropriate proactive and reactive strategies to address them.** Behaviours of concern, such as Dane's spitting behaviour, can meet several different functional needs of the person depending on the context. Detailed analysis is required to deeply understand the function of the behaviour, develop a formulation, and create a behaviour support plan that proactively supports the person to manage their psychosocial, emotional, sensory, and communication needs.

**Having highly skilled practitioners to undertake this work is essential.** Practitioners who are early in their career or new to working with people with disability require a high-level of support and supervision, particularly when working with clients like Dane, who have complex support needs. New graduate programs (such as The Benevolent Society's Graduate Pathway program for allied health professionals and Intensive Behaviour Intervention and Support (IBIS) program for behaviour support practitioners) provide additional learning and

<sup>33</sup> AssistiveWare (n.d.). *Proloquo2Go Crescendo Core*. <https://www.assistiveware.com/learn-aac/quick-communication-boards> Retrieved 23 July 2023.

<sup>34</sup> McWilliam, R.A. (2010). *Routines-Based Early Intervention: Supporting Young Children and Their Families*. Baltimore: Brookes.

<sup>35</sup> McWilliam, R.A., Boavida, T., Bull, K., Cañadas, M., Hwang, A.W., Józefacka, N., Lim, H.H., Pedernera, M., Sergnese, T. and Woodward, J. (2020). The routines-based model internationally implemented. *International Journal of Environmental Research and Public Health*, 17(22): 8308. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7697325/>

<sup>36</sup> Lee, S.C., Muccio, B.E., & Osborne, N.L. (2009). The effect of chaining techniques on dressing skills of children with moderate mental retardation: A single-subject design study. *Journal of Occupational Therapy, Schools, & Early Intervention*, 2(3-4), 178-192, DOI: 10.1080/19411240903392590

development for newly qualified practitioners. These programs help embed good governance so that children with a disability and their families can be assured of high-quality services that safeguard against harmful practices and maximise client, family, and community outcomes.

**The Benevolent Society is committed to delivering high-quality supervision as part of a robust practice and clinical governance framework.** This requires consumer-directed services, such as those delivered via the NDIS, to be priced accordingly. Clinical governance includes, but is not limited to, processes for employee screening, learning and development, ethical decision-making and review, clinical supervision, client outcomes monitoring, and restrictive practice governance.

**Table 1: Progress Towards Dane’s Communication Goal**

<b>Goal: For Dane to have access to a robust communication system for aided language stimulation</b>					
<b>Step</b>	<b>Sub-goal</b>	<b>Routine</b>	<b>Accuracy</b>	<b>Who is responsible</b>	<b>Achieved Y/N</b>
1	Dane will have <b>consistent access</b> to his core vocabulary board by ensuring one person in Dane’s immediate environment is always wearing the core board during daily routines	Before-school routine	4 out of 5 mornings	Mum	N (Implement visual schedule)
		During school hours	5 out of 5 school days	Lisa and Raj (Learning Support Officers) & Educators	Y
		After-school routine	4 out 5 afternoons	Mum	Y
2	Dane will experience <b>Aided Language Stimulation</b> for one home-based and five school-based activities across the day.	Arrival at school + four other activities each day	5 out of 5 school days	Lisa Raj Educators	
		Afternoon tea	4 out of 5 days	Mum (with a focus on modelling <i>eat, more, and finished</i> )	



## Appendix 4: The Benevolent Society's Early Years Places

The Benevolent Society Early Years Places engages and retains at risk families with effective parenting, infant and social supports. Children and their families often need broader supports than single programs can provide. This is why the Early Years Places are designed to wrap around families with targeted supports that can meet a range of social, emotional, and economic needs.

### **Extraordinary preventive work can be done where integrated early years services exist.**

What happens early in a child's life matters. The first five years deeply impact a child's future health, development, learning and wellbeing<sup>37</sup>. Integrated service offerings help to overcome the challenge of a disparate hard to navigate service system. Evidence shows the wellbeing of children improves when early childhood interventions can be wrapped around them and their families<sup>38</sup>. This benefit has been evident in the outcomes achieved in The Benevolent Society integrated Early Years Places, which are innovative one-stop shops that support the health, development, wellbeing, and safety of young families.

### **The Benevolent Society were the first providers of integrated early childhood care in Queensland.**

These Early Years Places currently support more than 4,400 young children and their families every year, including many families from First Nations and Culturally and Linguistically Diverse backgrounds. Their strength comes from an ability to engage vulnerable families, identify developmental and family risks early, and then retain families long enough for supports to have impact. This is done through the employment of a multidisciplinary staff across a range of universal and targeted early child development and support services, while also working in partnership with other non-government service providers, ACCOs and the Queensland Government. Children walk through the doors to access a range of services that can be tailored for each family in a non-stigmatising and family friendly way.

## **Why Early Years Places Work**

### **It is often the children and families who most need services that are more likely to miss out.**

Children living in disadvantaged communities are least likely to attend playgroups: 1 in 7 compared with 1 in 4 of those in more advantaged communities<sup>39</sup>. Children from Aboriginal and Torres Strait Islander communities are also less likely to attend playgroups, as are children from non-English speaking backgrounds - and when children with a First Nations background don't attend playgroups, they are almost twice as likely to be developmentally vulnerable at school entry, compared to those who attend<sup>40</sup>. Unfortunately, even when children attend early childhood education the impact can be limited if their families cannot access additional, targeted health and development parenting and social supports<sup>41</sup>. This is why engagement sits at the core of these Early Years Places - programs are designed and implemented with, and for, the community in which they operate and with other non-government service providers, Aboriginal and Torres Strait Islander community-controlled organisations and the Queensland Government.

### **They align with the current evidence base on what should work in early childhood systems.**

These Early Years Places are both consistent with, and build upon, the theoretical evidence base that has described what makes a strong, fully integrated, place-based support system for socially excluded families. Their strength comes from an ability to engage vulnerable families, identify developmental and family risks early, and then retain families long enough for supports to have impact.

<sup>37</sup> Council of Australian Governments (2009). *Investing in the early years—a national early childhood development strategy: an initiative of the Council of Australian Governments*. Council of Australian Governments

<sup>38</sup> Molloy C, O'Connor M, Guo S, et al. (2019) *Potential of 'stacking early childhood interventions to reduce inequalities in learning outcomes*. J Epidemiol Community Health

<sup>39</sup> AEDC Research Snapshot (2020) *The relationship between early childhood education and care and children's development*.

<sup>40</sup> Sincovich, A., Harman-Smith, Y., & Brinkman, S. (2019). *The reach of playgroups and their benefit for children across Australia: A comparison of 2012, 2015, and 2018 AEDC data*. Telethon Kids Institute, South Australia.

<sup>41</sup> Moore, TG (2019), *Early childhood, family support and health care services: An evidence review*, Prepared for the City of Port Phillip, Melbourne Victoria: Centre for Community Child Health

## They focus on creating a bridge between informal and formal assistance.

These are one-stop shops to support the health, development, wellbeing, and safety of families who have young children aged up to eight years. Families walk through the doors to access a range of services, including child health checks, immunisation services, or just to enjoy a playgroup with their child. Once through the door, staff have the capacity to ramp up and target interventions for a range of concerns that the family may bring with them.

## Early Years Places help families overcome structural, relational, and family barriers to engagement.

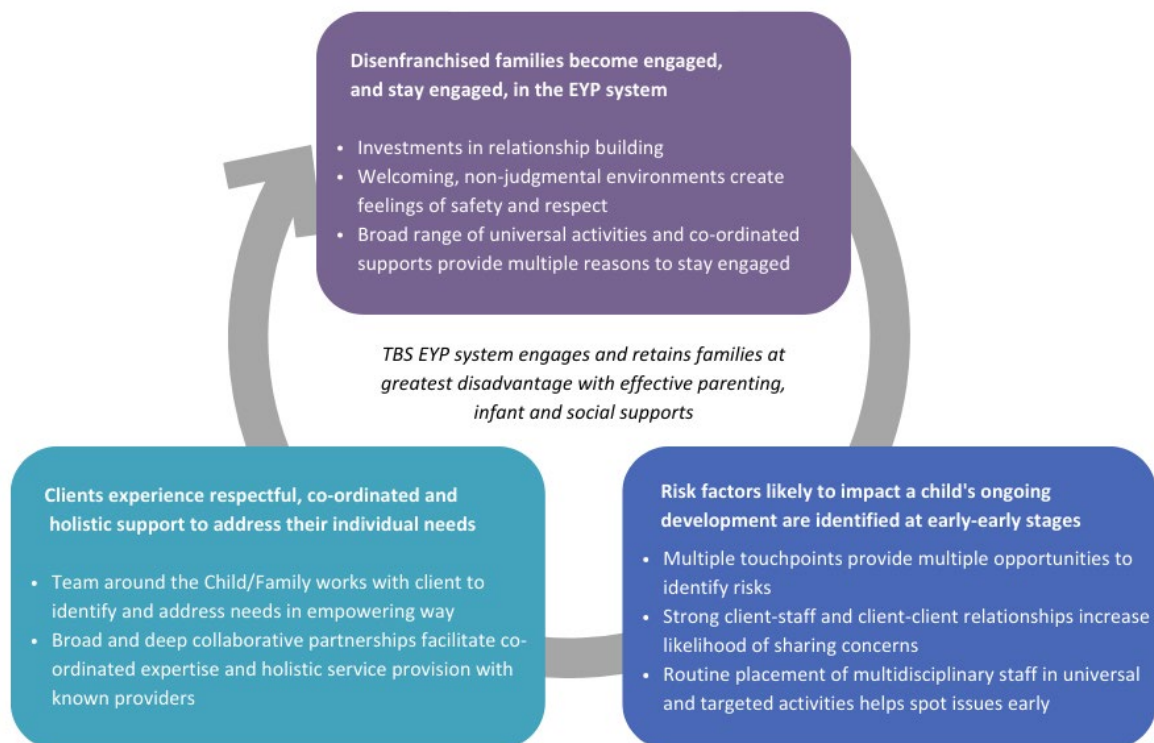
The Benevolent Society has found Early Years Places provide the key ingredients needed to engage vulnerable families:

- Investment in building trust and strong relationships with, and between, clients in a safe, culturally relevant, and welcoming environment with a universal service offering.
- Commitment to hiring expert staff with the relevant training, placing those staff in multiple settings, and coordinating targeted supports where required.
- Broad, strong, collaborative service partnerships providing a diverse and holistic offering of both universal and targeted activities and supports.
- Governance and practice frameworks providing a strong enabling environment.

The Benevolent Society has also discovered over time that the three key strengths of the Early Years Places lie in their ability to:

- Engage vulnerable families (high engagement rates);
- Identify developmental and family support risks at an early stage (early identification); and
- Retain families within the system for long enough that the supports have the desired impact (high uptake rates of identified supports).

Figure 1: Early Years Places approach to engaging and retaining families at greatest disadvantage.



## The Next Steps

Early research by our partners at Social Outcomes has shown through a breakeven analysis that it only takes one child in a cohort to 'do well' for the benefits to exceed the costs.

The key benefit supporting the breakeven analysis is the assumed reduction in predicted early school leaving rates derived from engagement with The Benevolent Society Early Years Places developmental and family supports. By reducing early school-leaving the risk of lifetime unemployment and associated social costs is also reduced. We have started building this evidence by establishing there is a breakeven point - that it only takes one child for the benefits to exceed the costs.

**But to realise their full impact and scale them up effectively, filling evidence gaps must also be a priority.**

We know Integrated support for children and their families work. The literature is full of reasons why integrated early childhood systems are better than fragmented service systems. However, The Benevolent Society's recent with Social Outcomes revealed the evidence-base is surprisingly without robust data. Right now, each organisation designs the impact measures of their integrated services however they see fit. Agreeing on a set of consistent impact measurement practices and learnings would change this, strengthening the evidence base. Measuring the social and economic value of integrated childhood supports in Australia is challenging – but if we are to realise the full impact of these initiatives and scale them up effectively, filling the evidence gaps must be a priority.

For more detail on the social impact read the full [Impact Measurement Framework and Report](#)

### Sarah's Story\*<sup>42</sup>

**30-year-old Sarah is in a de facto relationship and has a daughter, Michelle (3 years old) and a son, Jack (5 years old).** They live in social housing. Both the children and their father identify as being First Nations. Michelle and Jack are both experiencing developmental delays. Sarah left school in Year 9 and does not currently have a paying job. She has a long history of experiencing domestic family violence in the home, which has been regularly observed by her children. She wanted to separate from her partner but has struggled to navigate that process. Her partner controls the money, her phone and her access to family and friends. Sarah spends most of her time at home and is very cautious of people she doesn't know.

**Sarah found out about The Benevolent Society Early Years Program when her doctor at the local Aboriginal and Torres Strait Islander health service suggested she make contact.** After calling the service, Sarah was invited to bring Jack and Michelle to the Explorers Playgroup which is specifically designed for children experiencing developmental delays. Michelle and Jack love playing with the other kids and Sarah has felt great relief that she can talk about her parenting experiences with other parents going through similar challenges – suddenly she doesn't feel so different. It feels like a safe place she can come to where there is no judgement, just friends and staff who support her.

**Sarah quickly realises the staff are an amazing resource– with an occupational therapist, a speech pathologist and a child and family practitioner all under the same roof.** And the support continues, with the Early Years Place providing ongoing targeted support to help Sarah and her children stay on track. In addition to regular supervision provided to all staff, the Team Leader in charge of Sarah's case actively seeks the views from both Sarah and staff about how well the interventions are working and what they could do differently next time. This includes support seeking affordable housing, help finding a school that can best support Michelle's needs and then help to get Sarah a reduction in school fees.

**Over time, Sarah and her children experience secure housing, improved community connection and Michelle successfully transitions to school.**

<sup>42</sup> Sarah's Story is a condensed version of a case study developed as part of The Benevolent Society and Social Outcomes Impact Report on its Queensland Early Years Places – it represents a collection of experiences by families who engage with the EYP. The names do not depict any specific EYP family. **24**