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Office of the CEO

The Hon. Libby Coker MP
Chair
Joint Standing Committee on the NDIS
Inquiry into Capability and Culture of the NDIA

Via email: NDIS.joint@aph.gov.au

Dear Ms Coker

I thank the Joint Standing Committee on the NDIS (the Committee) members for taking the time to be briefed on the National Disability Insurance Agency's (NDIA's) Children's Taskforce at a private briefing on 12 September 2023 related to the Inquiry into the Capability and Culture of the NDIA.

To assist the Committee with its Inquiry, please refer to the below information in response to questions raised during this briefing.

1. Senator Reynolds requested more information about recent developments in Victorian Early Childhood Intervention Services, and how those services support National Disability Insurance Scheme (NDIS) participants.

The Victorian Government, Department of Education and Training (DET) recently announced 'The Best Start, Best Life reform' which includes an additional commitment of $1.8 billion over 5 years in early childhood education. This includes:

-   $546 million to support the continued roll out of the Best Start, Best Life reforms (includes three-year-old kinder);

-   $28 million to support language learning in early childhood centres;

-   $20 million to provide every service with grants for toys and equipment, create new and support existing toy libraries and fund Bush Kinder programs; and

-   $18 million to support young children with disability, developmental delay and/or additional needs.

The NDIA is in discussions with the Victorian DET on how it might better work together to improve the connection between mainstream services for children and the NDIS, including for children with developmental delay, so they get the support they need as early as possible with the aim of improving their inclusion and participation in their community and preparation for the start of school.

2. Senator Reynolds requested other examples of good models and practices in the area of early childhood that NDIA is looking at.

The NDIA works with a range of stakeholders with expertise and direct delivery experience in early childhood early intervention to identify models of best practice. The NDIA uses an evidence based approach to determining the supports and services that constitutes best practice through a range of mechanisms, including available contemporary research.

The NDIA delivers the current early childhood approach, through its early childhood (EC) partners. EC partners employ teams of early childhood professionals with experience and clinical expertise in delivering family-centred supports to children with disability and developmental delay. The EC partners work within local communities to connect children and their families with mainstream and specialist supports. The EC partners also use a range of methods to engage with children and families, trialling different approaches depending on need. For example some EC partners have specific strategies to work with children and their families in First Nations communities, others use tele-based supports to deliver therapy to children in remote areas.

In March 2020, the Independent Advisory Council to the NDIS released a paper on Promoting Best Practice In Early Childhood Intervention (ECI) in the NDIS, further information can be found at https://www.ndis-iac.com.au/advice. This advice informed the NDIA's early childhood early intervention (ECEI) reset project which commenced in late 2020. The NDIA also receives advice from the Independent Advisory Council's Children, Young People and Families Reference Group.

The NDIA regularly engages with the ECI Best Practice Network, a national network of early childhood peaks, who have a shared vision that evidence-based practices (inclusion, natural environments, key worker and family capacity building) are utilised widely in early childhood intervention as this provides the best opportunities for positives outcomes for children and families. An ECI Best Practice Network of not-for-profit providers of early intervention services and/or early childhood education have recently released a discussion paper titled 'Early childhood intervention and therapeutic supports for children and young people under age 16' and can be found at Attachment A.

3. Senator Steele-John requested more information about any Western Australian programs to assist children with disability or developmental delays, and how those programs integrate with the NDIS.

In Western Australia (WA) there is a long standing state-based system to support families whose children have developmental concerns or delays. A couple of examples include:

- Child Development Service (CDS) is delivered by the WA Government's Child and Adolescent Health Service. This service provides a range of assessment, early intervention and treatment services to children with developmental delay or difficulty in their impact on function, participation and/or parent-child relationship. Families are often referred to CDS as a first point of contact. From there the child may be referred to the NDIA (Partner – Wanslea) if there is evidence the child is likely to require supports through the NDIS. Further information can be found at https://cahs.health.wa.gov.au/Our-services/Community-Health/Child-Development-Service.

- Rocky Bay – Early Start Intervention Program (ESIP) is an evidence based program aimed at providing children (who are not NDIS participants and live within the Perth Metropolitan area) with access to specialist and comprehensive therapy services and support. The ESIP program is a 12 month program specifically targeted towards children (under 5) displaying signs and symptoms of significant developmental delay and/or developmental regression as well as risk factors associated with rare disease. Further information on ESIP can be fount at https://www.rockybay.org.au/.

- There are also 22 state funded Child and Parent Centres across WA. The Child and Parent Centres provide a range of easily accessible programs and services for families, including parenting programs, early learning programs, maternal and child health services, and child support activities. The NDIA (Partner -Wanslea) may refer children and their families to this mainstream program during early connections. Further information can be found at https://childandparentcentres.wa.edu.au/.

4. Dr Ryan requested more information about the Telethon Kids pilot program in WA, including details of the partnership with WA Health and the Department of Communities.

The NDIA is funding a pilot program that will examine the effectiveness of pre-emptive intervention for infants showing early signs of autism.

The pilot program, known as Inklings is being delivered by the Telethon Kids Institute (TKI), and to ensure that there is an appropriate pathway of support for infants and parents, the WA Government's Child and Adolescent Health Service (CAHS) and Western Australia Country Health Service (WACHS) are supporting the delivery of the pilot program. These services will identify infants through their routine health screening programs, or from health professionals when parents observe atypical development.

The pilot program will run for three years at sites across Perth and regional WA for approximately 700-850 children in clinics or via telehealth.

The intervention comprises of:
   a) educating parents/cares; and
   b) building their capacity to undertake daily interactive play activities with their child during the period of rapid brain development in an infant (generally between 9-16 months).

5. You requested the research that was mentioned regarding the question of inequity in rural and regional communities.

The research referred to in the meeting has been undertaken by the Melbourne Disability Institute, University of Melbourne with a focus on NDIS plan utilisation for Culturally and Linguistically Diverse, First Nations and participants living rural and remote locations. This research was commissioned by the NDIS Review and once finalised it will be published alongside the Review's findings. I therefore anticipate that the research will be released in October 2023.

The draft research estimates the differences in spending on NDIS supports and NDIS plan values between cities, regional centres, and rural areas and finds that participants who live in regional and remote areas have only a marginal difference over those who live in major cities.

Delivered by the
National Disability
Insurance Agency

6. You also requested any further information on initiatives focused on connecting families with communities and other families going through similar experiences.

The Department of Social Services in collaboration with the NDIA released a report on *Peer support for families with young children with disability and developmental concerns* in 2022 to support the implementation of Australia's Disability Strategy Early Childhood Targeted Action Plan (EC TAP). The report can be found at <u>Attachment B</u> and confirms the value of peer support and describes benefits that include increased confidence, a sense of belonging and a positive sense of community.

The NDIA subsequently developed a resource for its early childhood partners to share information with families about the value of peer support and how to connect with peer supports in their community. There is also acknowledgement of the value of peer support embedded in the NDIA's operational guidelines which are used by NDIA staff working with children and their families.

I trust this information is of assistance to the Committee.

Yours sincerely

Rebecca Falkingham
Chief Executive Officer
National Disability Insurance Agency
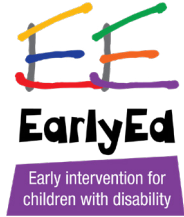
28 September 2023

Encl:

Attachment A - Early childhood intervention and therapeutic supports for children and young people under age 16
Attachment B - Peer support for families with young children with disability and developmental concerns

DISCUSSION PAPER

Early Childhood Intervention and
Therapeutic Supports for Children and
Young People under Age 16

MARCH 2023

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ABOUT THE AUTHORS

This paper has been prepared by a network of fourteen (14) not-for-profit providers of early intervention services and/or early childhood education. We are informally calling our network the *Early Childhood Intervention (ECI) Best Practice Network*. Together, we support over 4,788 children annually in early intervention under the NDIS and over 16,873 children and young people annually in total. We primarily operate across NSW, VIC and the ACT.

See **Appendix B** for a detailed outline of all providers who have contributed to this paper.

INTRODUCTION AND PURPOSE

The *ECI Best Practice Provider Network* is a group of not-for-profit Early Childhood Intervention providers who collectively prepared this Discussion Paper on a voluntary basis.

Our shared vision is that evidence-based best practices are utilised widely in early childhood intervention as this provides the best opportunities for positive outcomes for children. We believe that this vision will support the current and long-term sustainability of the National Disability Insurance Scheme (NDIS) and community service systems and will increase positive outcomes for children and families. We believe our vision is well-aligned to the vision of the National Disability Insurance Agency (NDIA) and State governments.

Our paper takes a 'whole of government' view as children are engaged with multiple service types at different government levels across their lives. The introduction of the NDIS has changed the service system landscape. This new landscape and service system requires reflection and review to ensure that the shared vision and outcomes are being realised.

Our fear is that without system changes, there will be long-term strain placed on health, community services, education services, and the NDIS may not be sustainable.

We believe that the NDIS has made significant differences to the lives of all children and provides families with greater choice and control over their child's future. However, the NDIS is an adult-centric model, and the structures within it do not always fully meet children's needs. The *ECI Best Practice Network* fully supports the current NDIS Review initiative and Early Years Strategy consultations which are currently underway. Both of these initiatives provide timely opportunities for review.

In this paper, we have summarised our observations and concerns with the current early childhood early intervention system and have put forward some potential solutions and recommendations to help start a discussion regarding the way forward.

DISCLAIMER

The paper is intended to help inform policy-makers and decision-makers regarding observations 'on the ground' from a provider-perspective. These observations are made from cases we have observed and direct experiences. The paper is intended to summarise these and to put forward possible solutions and recommendations which we hope will help to constructively contribute toward shaping system solutions that are robust, achievable and meet the 'Best Practice Guidelines'[1] in Early Childhood Intervention.

We acknowledge that consultation with other key stakeholders directly would be warranted prior to modelling and implementation of any possible solutions discussed. We fully support broader engagement with these stakeholders and more robust discussion to ensure solutions implemented are the right fit.

Our intention is to put forward information and possibilities which will serve as a platform for consideration, review, consultation, and solutions-thinking.

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[1] The Best Practice Guidelines for Early Childhood Intervention commissioned by the Australian Government in 2015. https://re-imagine.com.au/practitioner/what-is-best-practice/

Early Intervention | Summary of Recommendations

IMPROVING ACCESS

01 **Ensure a 'No Wrong Door Approach' for families** when engaging with early access services. In NSW, restructure funding to enable individualised support to families accessing TEI services (such as playgroups) so those local services can specifically help families navigate the service system.

02 **Inclusion Capacity Building Support** – Ensure all early childhood education services have ongoing capacity building funding to support inclusion. In NSW, require Sector Capacity Building services to provide localised approaches and to assist with inclusion and management strategies for individual cases in local services. This will build service capacity in inclusive practices to support the individual child and increase their own capacity to include children in the future.

03 **Inclusion Support in Early Childhood Education settings** – Ensure all early childhood education services have sufficient funding to guarantee inclusion for children with high learning support needs by reviewing the hours funded and the rate of pay per hour. And provide funding for early intervention for children who cannot access the NDIS or other schemes.

04 **School access for early intervention** – Review Department of Education policies and procedures regarding access to early childhood intervention specialists and allied health professionals for children to ensure an access and equity, in alignment with the Best Practice Guidelines.

05 **Funding for preventative programs** – Ensure funding is available for preventative programs including prenatal supports and postnatal supports. For instance, in NSW, renew the Start Strong Pathways Program funding.

COMMUNITY HEALTH

01 Revise working protocols between States/Territories and the Commonwealth regarding Tier 2 supports (e.g., supports which are not funded by the NDIA).

02 Increase funding for Child and Family Health Nurses within Community Health and other health services (e.g., Brighter Beginnings in NSW).

03 Revise Community Health protocols to include a focus on family health and wellbeing, not just child.

04 Maintain a 'no wrong door' approach to access so that where Community Health does not have capacity, there are ways to commission local providers to provide services and supports.

GPS/PAEDATRICIANS/MEDICARE

01 **Short Term**
Implement widespread and targeted education campaigns for medical practitioners and the public regarding the Best Practice Guidelines.

02 **Medium Term**
Review the structure, price and quantity of the Medicare funding to align to Best Practice Guidelines as well as meet demands of families.

ECI PARTNERS

01 Separate the ECI Partner role from the NDIA; maintaining the information and advice and assessment functions of the ECI Partner role.

02 Require ECI Partners to refer to local registered providers for Short Term Early Intervention work to give families more choice and control.

03 Commission local registered providers to deliver Short Term Early Intervention and set KPIs on timeframes to connect and deliver services to families to ensure a timely response.

Short Term

01 Address the lack of representation on the NDIS Board by recruiting with Directors who have personal or professional experience with early childhood services. As almost 50% of NDIS participants are children, the Board should proportionally reflect this in time – with a target to have 25% representation by 2024 and 50% by 2025.

02 Establish a children's portfolio within the NDIA to enable better oversight of this area.

03 Ensure NDIS plans support informed choice and control and reflect the Best Practice Guidelines, i.e. inclusion, natural environments and family capacity building are encouraged and funded.

04 Change the structure of the price guide to encourage use of funding within the Best Practice Guidelines. For example, one option would be to restructure the funding and Price Guide to provide separate 'buckets' of funding for:

- **Travel –** so families will not see this as reducing their direct services and will be encouraged to use this funding and access services in natural settings.
- **Key Workers** – so families will not see this as reducing their direct services and will be encouraged to use this funding.
- **Capacity Building** – so families will be encouraged to use this funding.
- **Family Supports** – so families will be able to access family therapy, support for siblings, capacity building, and even household support as required.

05 Require or incentivise families to use only registered providers for Early Childhood Early Intervention and Therapeutic Services to age 16.

06 Include audit on the delivery of services within the Best Practice Guidelines into existing NDIA registration system. This could include setting guidelines such as the % of sessions which have parent involvement and % of sessions in natural settings.

Medium Term

07 Develop an accreditation for Key Workers and make that a requirement of delivery of Key Worker services.

08 Require participants to be NDIA Managed for the first 2 years so they can build capacity through their engagement with existing registered providers who will serve a role in educating them through capacity building.

09 Commission research to develop Best Practice Guidelines that cover the ages of 8 to 16 years.

Short Term

01 Expedited visa processes for allied health professions.

02 Review NESA requirements to account for this type of community work.

03 Review the E*ducational Services (Teachers) Award* to account for this type of community work.

04 Provide financial subsidies to providers who employ new graduates for their first two (2) years of employment (similar to other approaches for trainees).

05 Invest in the development and delivery of Post Graduate accredited training in the Best Practice Guidelines for Early Childhood Early Intervention, including the Key Worker model. This has recently been an initiative for other areas such as:

a. Developmental Educators
b. Behaviour Support Practitioners
c. Play Therapists

06 Provide immediate training for staff of registered providers regarding delivery of early childhood early intervention in the Best Practice Guidelines. This training should be free for providers.

07 Development of clear workforce strategy for early intervention and allied health to complement other existing workforce strategies.

08 Provide incentives for study in the allied health and early childhood teaching professions.

Long Term

09 Work with universities and accrediting bodies to ensure the Best Practice Guidelines for Early Childhood Early Intervention, including the Key Worker model, are a requirement of curriculum.

Early Intervention | Best Practice

Best Practice in Early Childhood Intervention

In 2018, the National Disability Insurance Agency (NDIA) funded the development of the national guidelines for early childhood intervention titled "Best Practice in Early Childhood Early Intervention," which were drafted by Early Childhood Intervention Australia (ECIA) (now Reimagine). These Guidelines set out four (4) pillars underpinning best practice, which are outlined below.

QUALITY AREA 1: FAMILY

- Family-centrered and Strenghts-based Practice
- Culturally Responsive Practice

QUALITY AREA: INCLUSION

- Inclusive Participatory Practice
- Engaging the Child in Natural Environments

QUALITY AREA 3: TEAM WORK

- Collaborative Teamwork Practice
- Capacity-Building Practice

QUALITY AREA 4: UNIVERSAL PRINCIPLES

- Evidence Base, Standards, Accountability and Practice
-Outcome-Based Approach

The NDIS website[2] elaborates on the 'Best Practice Guidelines in Early Childhood Intervention' (henceforce, 'Best Practice Guidelines'):

THESE GUIDELINES TELL US THAT CHILDREN AND FAMILIES BENEFIT THE MOST WHEN WE BASE EARLY CHILDHOOD INTERVENTION ON THE FOLLOWING:

- *The family is at the centre of all services and supports - the family and early childhood professionals work together in partnership. Services and supports are based on the family's needs and choices.*

- *All families are different and unique - services and supports are delivered in a way that is respectful of a family's cultural, language and social backgrounds, and their values and beliefs.*

- *The child is included at home and in the community - the child takes part in home and community life, with supports as needed, to create a real sense of belonging.*

- *The child practises and learns new skills everyday - the child learns and practises skills in the activities and daily routines of their everyday life.*

- *Early childhood professionals and family form a team around the child - a family works together with early childhood professionals to form a team around the child. They share information, knowledge and skills. One main person from this team, called a key worker, may be allocated to work with the family.*

- *Supports build everyone's knowledge and skills - building the knowledge, skills and confidence of the family and the important people in a child's life will have the biggest impact on a child's learning and development.*

- *Services and supports work with the family on the goals they have for their child and family - early childhood professionals focus on what parents or carers want for their child and family, and work closely with the family to achieve the best outcomes for their child.*

- *Early childhood professionals deliver quality services and supports - early childhood professionals have qualifications and experience in early childhood development, and offer services based on sound evidence and research.*

Best practice recognises that children learn and develop in natural, everyday settings.

This includes their own home, and other places, such as childcare, playgroup, kindergarten or preschool, where they play with family or friends. This means the adults they are with need information, tools and support to help the child's development and participation.

Being included in these everyday activities gives children with developmental delay or disability the same opportunities as all children.

It provides them with opportunities to develop friendships, interact with others and be a part of their community.

Best practice not only takes into account broad early childhood intervention research, but also evidence relating to the needs of children with a specific diagnosis, such as autism spectrum disorder or cerebral palsy.

We seek to highlight where the system is preventing these principles from being realised, and offer solutions that will enable Best Practice to be applied across diverse settings and systems.

Desired Outcomes of the Current System

The graphic below outlines the intended objectives required to be realized to enable an 'optimal child mental health and wellbeing system' in the *National Children's Mental Health and Wellbeing Strategy* published in 2021 by the National Mental Health Commission (p. 8):
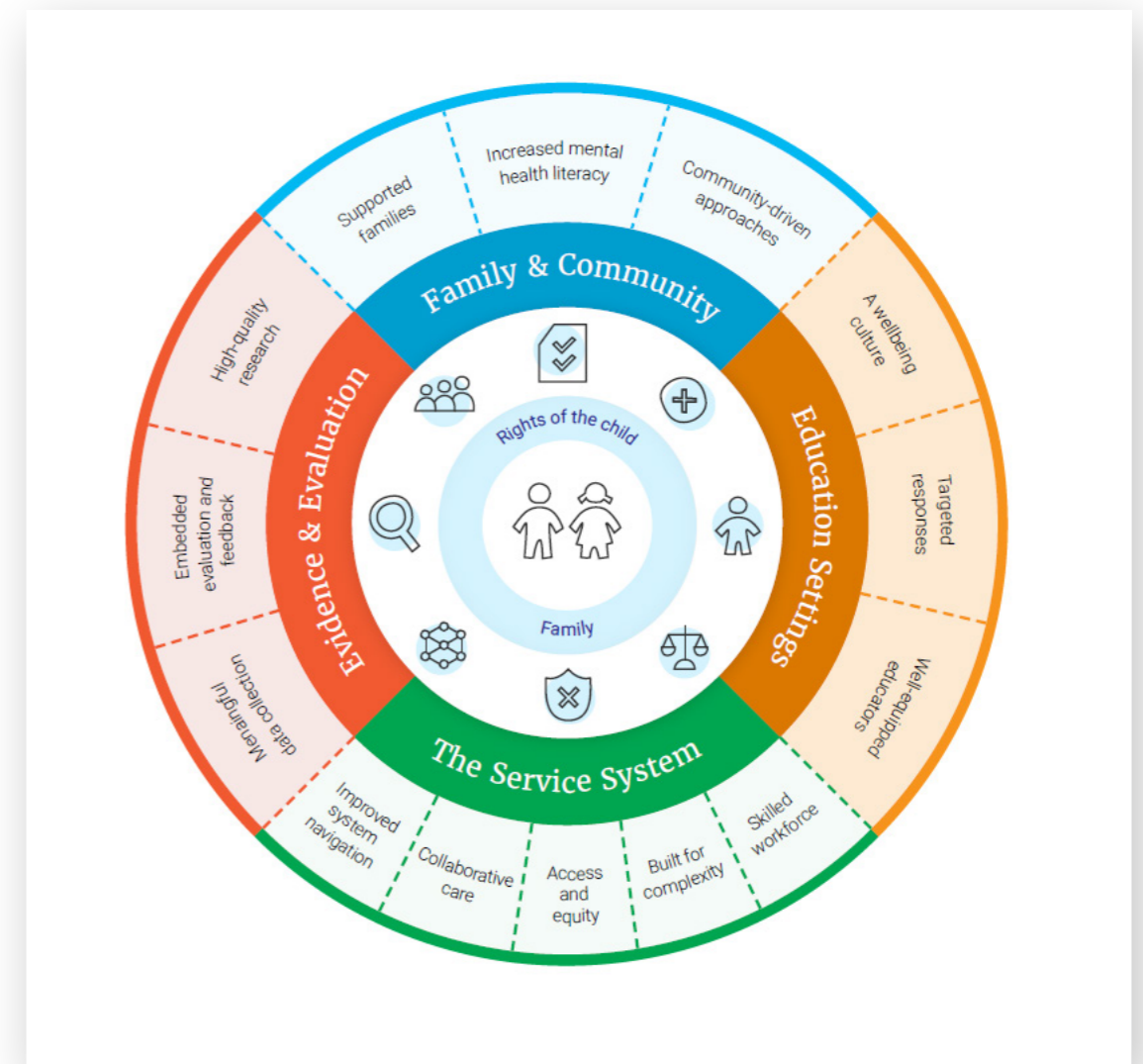
We believe these objectives are also shared by the NDIA and other service systems, not just the mental health system. We are concerned that these objectives are not being fully met by the current system as a whole.

In this paper we summarise concerns with both alignment to the Best Practice Guidelines and the achievement of the desired outcomes of the system for families and children.
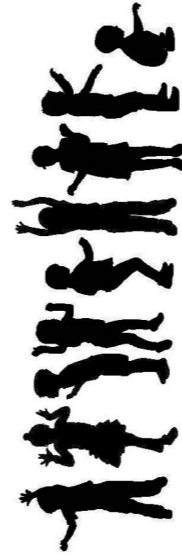
Early Intervention | The Current System

The National Disability Insurance Scheme (NDIS) created the Early Childhood Approach to provide a pathway for children under the age of seven to access supports which will enable parental capacity, inclusion in society, and positive long-term outcomes for the children involved. The system is not designed to stand alone, rather to sit within other systems that support children and families at different points on their journey.

However, from our collective experience, the way in which children and families currently access early intervention can be confusing, delayed and disparate, resulting in children who vitally need these supports not gaining access to them at the most crucial time in their development.
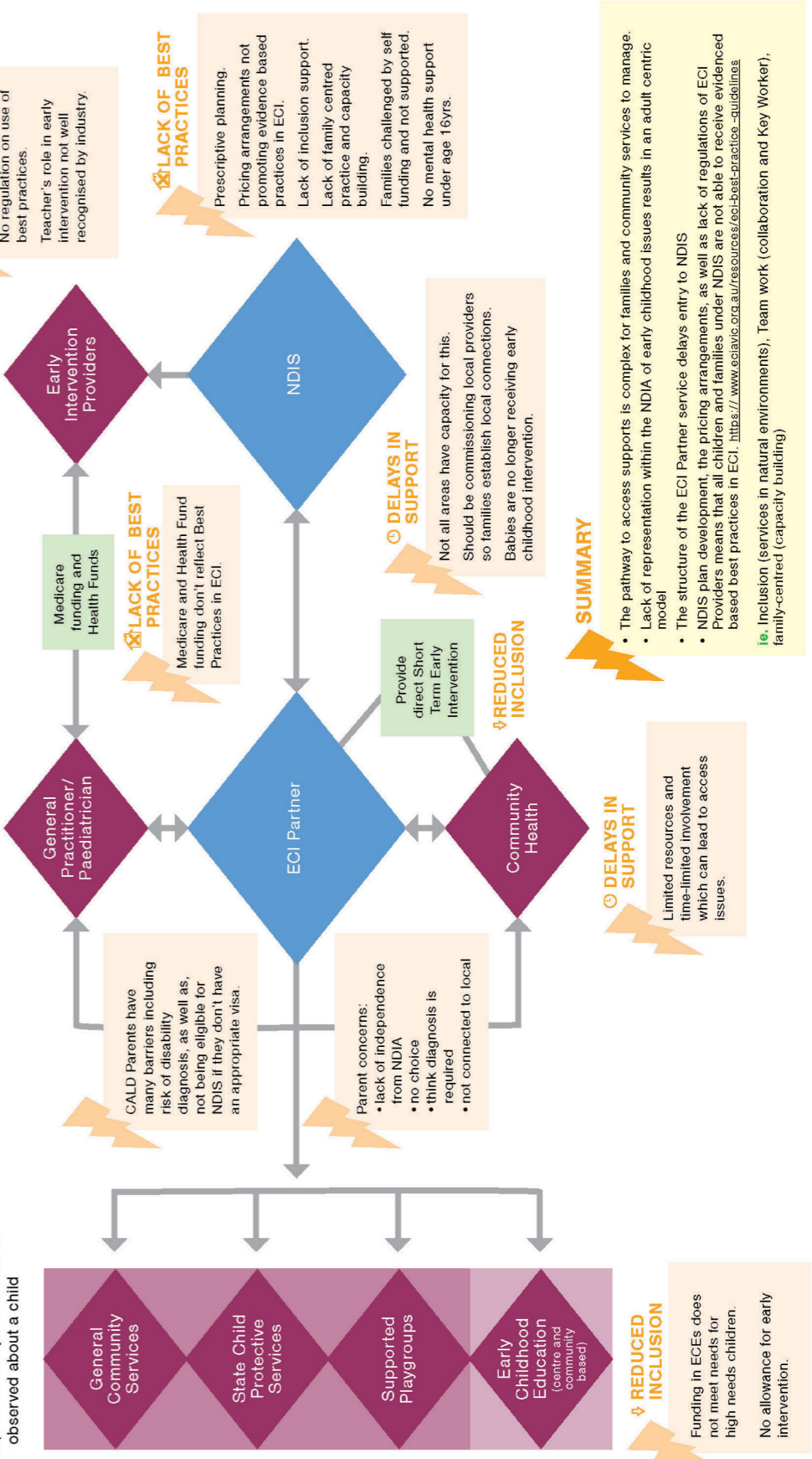
For children experiencing developmental delay or disability, their families and carers are faced with a complex network of services, application processes and funding streams before they can even access early intervention supports. Even with the best of intentions, the current system can be difficult to navigate and creates burdens and barriers for families, which in turn fails to facilitate smooth access to services.

In this graphic, we summarise the current service system as a whole and areas where we believe there are challenges for families and children.

CHALLENGES WITH THE EARLY CHILDHOOD INTERVENTION SERVICE SYSTEM UNDER THE NDIS

Developmental delays or concerns observed about a child

⊠ LACK OF BEST PRACTICES
High regulatory costs.
No regulation on use of best practices.
Teacher's role in early intervention not well recognised by industry.

⊠ LACK OF BEST PRACTICES
Prescriptive planning.
Pricing arrangements not promoting evidence based practices in ECI.
Lack of inclusion support.
Lack of family centred practice and capacity building.
Families challenged by self funding and not supported.
No mental health support under age 16yrs.

Early Intervention Providers

NDIS

⊘ DELAYS IN SUPPORT
Not all areas have capacity for this.
Should be commissioning local providers so families establish local connections.
Babies are no longer receiving early childhood intervention.

◆ LACK OF EQUITY
Medicare funding is insufficient to cover costs, creating equity issues for low income families.

Medicare funding and Health Funds

⊠ LACK OF BEST PRACTICES
Medicare and Health Fund funding don't reflect Best Practices in ECI

Provide direct Short Term Early Intervention

⬇ REDUCED INCLUSION

ECI Partner

General Practitioner/ Paediatrician

Community Health

⊠ LACK OF BEST PRACTICES
Lack of understanding of best practice model–medical model promoted.

CALD Parents have many barriers including risk of disability diagnosis, as well as, not being eligible for NDIS if they don't have an appropriate visa.

Parent concerns:
• lack of independence from NDIA
• no choice
• think diagnosis is required
• not connected to local

⊘ DELAYS IN SUPPORT
Limited resources and time-limited involvement which can lead to access issues.

General Community Services

State Child Protective Services

Supported Playgroups

Early Childhood Education (centre and community based)

⬇ REDUCED INCLUSION
Funding in ECEs does not meet needs for high needs children.
No allowance for early intervention.

SUMMARY
• The pathway to access supports is complex for families and community services to manage.
• Lack of representation within the NDIA of early childhood issues results in an adult centric model
• The structure of the ECI Partner service delays entry to NDIS
• NDIS plan development, the pricing arrangements, as well as lack of regulations of ECI Providers means that all children and families under NDIS are not able to receive evidenced based best practices in ECI. https://www.eciavic.org.au/resources/eci-best-practice-guidelines

ie. Inclusion (services in natural environments), Team work (collaboration and Key Worker), family-centred (capacity building)

The System | Opportunities for Improvement

We have used our combined experience to articulate the areas of the system that that we have observed to pose challenges to children accessing early intervention and achieving positive outcomes. We have also included potential solutions and recommendations that could be implemented by various arms of government through funding or policy changes, which we believe would achieve significant positive outcomes for hundreds of thousands of families, whilst also delivering social and economic benefits for the Australian community as a whole.

1.   Early Access Points

Children may be identified as 'at risk', having developmental delays or other concerns by many mainstream settings. We have outlined four primary pathways in which children and families may be identified, but acknowledge there may be many others:

    a. General community-based programs;
    b. Supported community playgroups;
    c. State child protection services;
    d. Early childhood education services (centre-based and community-based).

In an ideal system, these services would be focused on both prevention, as well as, supporting children and families when concerns are identified. This local approach is powerful as these services are often less bureaucratic and therefore, are more accessible to families, especially those from multicultural backgrounds. Their local nature also enables them to connect personally with families, have staff with similar backgrounds and experiences, and connect families with local supports.

We believe that an unintended consequence of the current system is that generally families find it difficult to navigate and access support needed that is crucial in the early part of their journey. Furthermore, families that have any disadvantages (e.g., socially, culturally, or financially), experience further service gaps, delays and distress (Purcal, Hill & Meltzer, 2018).

GENERAL COMMUNITY-BASED PROGRAMS, SUPPORTED PLAYGROUPS, AND STATE CHILD PROTECTION SERVICES

LACK OF PREVENTATIVE FOCUS

We believe there is generally an insufficient focus on prevention within community settings. We believe more work can be done in the pre-natal period to support pregnant individuals and their partners to prepare for birth and the early years, as well as, more post-natal education and support services. For instance, outside of the hospital system, very little is done to educate families before their children are born. Further, once children are born, very few programs target the first year or two of a child's life, with most funded services focusing on the preschool years. Child protection services and related family-supports do exist, but typically are only involved when a family has already hit risk of significant harm or crisis. Education and family support focused on prevention could prevent many families from reaching this point.

LIMITATION OF CURRENT FUNDING MODELS

Recent funding models (e.g., Targeted Earlier Intervention in NSW, also known as 'TEI') have reduced capacity for case management support and individualised support models for some programs such as playgroups. Therefore, when concerns are identified, services have limited capacity to work closely to help families reach the support they need. For instance, families are often referred back to playgroups for early intervention, but playgroups are not funded to provide ongoing individual support to help the family navigate the system and access supports. While there are some intensive programs funded, their capacity is limited.

EARLY CHILDHOOD EDUCATION SERVICES (BOTH CENTRE-BASED AND COMMUNITY-FUNDED PROGRAMS)

FUNDING LIMITATIONS WHICH HINDER INCLUSION

The structure and support of funding[3] in early childhood education services does not meet the needs for children with developmental delays, disabilities or other high learning support needs. This can leave services to subsidise costs or preclude inclusion for some children. For example:

To access funding, the funder may state that diagnosis is not required. In our experience, in almost all cases, a diagnosis is required to access funding. This restricts access to many children who cannot afford or access a diagnosis and ignores the long-term considerations with diagnoses.	The funding is primarily used for staffing and is underfunded with rates at approximately $24 an hour. This does not cover base market rates, on costs including superannuation, supervision or other true and genuine costs for early child-hood staff, leaving the provider to subsidise.	The funding does not allow for direct intervention from other key professionals who are important in the 'team around the child' – where children are not eligible for NDIS, this leaves a significant gap in intervention supports for these children.

In long day care, the funding supports a limited number of hours per day which does not enable full inclusion for those children.

[3] Funding includes Inclusion Support funding for long day cares; High Learning Support Needs funding for NSW community preschools

INCLUSION SUPPORT AND ADVICE TO UPSKILL CENTRES IS LIMITED

For instance, in NSW, the Sector Capacity Building Program which is funded to support early childhood education centres to enable inclusion in their centre has been contracted to a small number of new providers in July 2022. In some areas (but not all), the supports are now generic and do not take into account the local community needs. Further, they do not assist providers directly with individual children's needs, leaving gaps which may preclude some providers from offering supports to those children.

COMMUNITY PROGRAMS TO ENABLE ACCESS TO EARLY LEARNING OPERATE IN UNCERTAIN CONDITIONS

For instance, in NSW, the Start Strong Pathways Program's future is uncertain. This program is funded to help 'hard to reach' and 'vulnerable' families to access early childhood education. There is a need for continued funding to ensure that these children are accessed so they don't miss out on essential early intervention.

COLLABORATION BETWEEN EARLY CHILDHOOD INTERVENTION AND MAINSTREAM SERVICES IS NOT ALWAYS EXPECTED

This presents a challenge regarding families' choice and control as it comes down to the service's capacity and willingness to collaborate (Purcal, Hill & Meltzer, 2018). For example, most of us have experienced that in NSW a School Principal will need to approve supports within the school. Some schools are unwilling to have early childhood early intervention specialists or allied health professionals enter the school, especially when they may have their own resources. This may lead to a disconnect in service delivery if children are not able to access those services in a school setting, or if they see one practitioner at school and another in the community. Furthermore, there is often a delay in start times of schools as most schools have policies and procedures that state any allied health are not permitted to start service delivery for 2-6 weeks of the start of the school year, a critical time to help a child integrate. While this is not universal for all schools, it is a common experience which can limit supports to children and families.

POSIBLE SOLUTIONS AND RECOMMENDATIONS - IMPROVING ACCESS

01 Ensure a 'No Wrong Door Approach' for families when engaging with early access services. In NSW, restructure funding to enable individualised support to families accessing TEI services (such as playgroups) so those local services can specifically help families navigate the service system.

02 Inclusion Capacity Building Support – Ensure all early childhood education services have ongoing capacity building funding to support inclusion. In NSW, require Sector Capacity Building services to provide localised approaches and to assist with inclusion and management strategies for individual cases in local services. This will build service capacity in inclusive practices to support the individual child and increase their own capacity to include children in the future.

03 Inclusion Support in Early Childhood Education settings – Ensure all early childhood education services have sufficient funding to guarantee inclusion for children with high learning support needs by reviewing the hours funded and the rate of pay per hour. And provide funding for early intervention for children who cannot access the NDIS or other schemes.

04 School access for early intervention – Review Department of Education policies and procedures regarding access to early childhood intervention specialists and allied health professionals for children to ensure an access and equity, in alignment with the Best Practice Guidelines.

05 Funding for preventative programs – Ensure funding is available for preventative programs including prenatal supports and postnatal supports. For instance, in NSW, renew the Start Strong Pathways Program funding.

2.   Formal Services to Enable Early Intervention

When concerns are identified regarding children's development, they are typically referred to or reach out to one of the more formal services which are equipped to assist them with accessing early intervention. Here we focus on the following services:

    a. Community Health Services;
    b. General Practitioners/Paediatricians;
    c. Early Childhood Early Intervention Partners (Partners in the Community).

Generally, for the first two areas particularly, there is a lack of understanding of the Best Practice Guidelines. We will outline some of the specific implications in each area below.

A. COMMUNITY HEALTH SERVICES

We acknowledge that the approach to community health differs in each State and Territory, and even regions within these. However, we believe that the following challenges are experienced across all areas:

It is often unclear whether community health or the NDIA is responsible when developmental concerns arise; this can lead to access delays. In young children, early and timely access to support is critical.

In some areas, diagnostic assessments to identify delay or disabilities, can be funded and provided by community health, but in other areas, this capacity does not exist, leading to access and equity concerns. The NDIA does not fund assessments.

In some States and regions (particularly metro-areas), resources for Child and Family Health Nurses have been strained or are insufficient to meet demand, meaning children are only monitored through 6-16 weeks. This can lead to a significant gap in time where a child is not getting regular developmental checks. While children will typically be seen for immunisation/Blue Book reviews, General Practitioners do not always have capacity to do thorough developmental reviews.
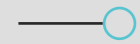
In some cases, focus is on the child's health and not the overall health of caregivers. Family support is an important part of the Best Practice Guidelines.

## POSSIBLE SOLUTIONS AND RECOMMENDATIONS – COMMUNITY HEALTH SERVICES

01 Revise working protocols between States/Territories and the Commonwealth regarding Tier 2 supports (e.g., supports which are not funded by the NDIA).

02 Increase funding for Child and Family Health Nurses within Community Health and other health services (e.g., Brighter Beginnings in NSW).

03 Revise Community Health protocols to include a focus on family health and wellbeing, not just child.

04 Maintain a 'no wrong door' approach to access so that where Community Health does not have capacity, there are ways to commission local providers to provide services and supports.

B. GENERAL PRACTITIONERS/PAEDIATRICIANS/MEDICARE

Whilst accessing supports through General Practitioners/Paediatricians, families are often provided Medicare referrals under Chronic Disease Management Plans.

The structure of the funding provided for children through Medicare does not align to Best Practice Guidelines.

Medicare funding provides for a maximum of five sessions. Generally, five sessions is insufficient time to provide appropriate support. In addition, it does not account for:
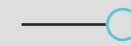
Time to liaise with other professionals under the 'Team Around the Child' transdisciplinary approach.

Time to complete reports back to the medical practitioner or other parties.

Funding is only for clinic-based appointments which does not align to the Best Practice Guidelines to work in natural settings.

There is no funding to support families as is expected as part of the Best Practice Guidelines. Even if parents receive separate funding personally for a 'Mental Health Care Plan' it does not cover couples counselling, requires a diagnosis, and is limited in the number of sessions available.

Further to this, the Medicare rebate per session is $56.00. This funded amount is insufficient and leaves families with either large gaps to fund privately (causing access and equity issues for families who cannot afford to do so), or services must wear this cost in some way.

In addition to challenges with the structure of Medicare funding, there is a general approach seen from General Practitioners and Paediatricians that promotes the 'medical model' rather than best practice. This is discussed further in the next section.

POSSIBLE SOLUTIONS AND RECOMMENDATIONS – GPs/PAEDATRICIANS/MEDICARE

01 **Short Term**
Implement widespread and targeted education campaigns for medical practitioners and the public regarding the Best Practice Guidelines.

02 **Medium Term**
Review the structure, price and quantity of the Medicare funding to align to Best Practice Guidelines as well as meet demands of families.

C. EARLY CHILDHOOD EARLY INTERVENTION (ECI) PARTNERS (PARTNERS IN THE COMMUNITY)

We acknowledge that the vision of these ECI Partner roles was to streamline access for families. Unfortunately, however, there have been some unintended consequences of this approach which have profound impacts. These include, but are not limited to:

There is only one partner per area which means families do not have 'choice and control' – a key tenant of the NDIS model. Where families have a poor experience directly or indirectly with a partner, they may not pursue early intervention.

ECI Partners are connected to the NDIA through their role in planning. This can be a barrier for families who are not ready or able to see their child as having a 'delay' or being 'disabled.' This is particularly challenging for multicultural communities.

The ECI Partners are tasked with providing 'information and advice' but in our opinion, cannot independently do so given their connection to the NDIA.

The ECI Partners are tasked with community awareness but many providers do not have the local connections required for this given their broad coverage area.

The ECI Partners are tasked with assessments but this is not independent from the NDIA.

The ECI Partners are funded to provide 'short term early intervention' – this is problematic because:

- There is no choice and control for the family regarding who provides this;
- This does not enable families to connect with local services which strengthens their broader support network;
- This pulls specialist workforce from other providers, straining the market workforce;
- Some ECI Partners do this and others do not – e.g., in more regional areas.

POSSIBLE SOLUTIONS AND RECOMMENDATIONS – ECI PARTNERS

01 Separate the ECI Partner role from the NDIA; maintaining the information and advice and assessment functions of the ECI Partner role.

02 Require ECI Partners to refer to local registered providers for Short Term Early Intervention work to give families more choice and control.

03 Commission local registered providers to deliver Short Term Early Intervention and set KPIs on timeframes to connect and deliver services to families to ensure a timely response.

3. National Disability Insurance Scheme and Funded Services

We acknowledge the significant improvements brought about by the introduction of the NDIS as a service system. We support the NDIS and want to ensure it remains a viable and sustainable long-term solution for Australians.

Generally, it is our observation that the design of the NDIS is 'adult-centric' despite 49.73%[4] of its participants being children. This means that well intended policies are having unintended negative consequences on children and families which impedes the ability to recognise the desired outcomes. Failure to recognise these outcomes can lead to longer term dependence on systems and a strain on the long-term sustainability of the NDIS. Early intervention and childhood services are an investment for the future and, if structured well, can promote the long-term sustainability of the system.

A. LACK OF EARLY CHILDHOOD REPRESENTATION

Generally, there is no representation of early childhood and childhood support on the NDIS Board and no dedicated department, which may be contributing to a lack of understanding of best practice and how deliverables in this space can lead to more positive long-term outcomes for participants and sustainability of the Scheme. With almost 50% of NDIS participants being children, and steadily increasing, early childhood expertise is required on the Board and at the NDIA.

B. STRUCTURE OF PRICE GUIDE

The structure of the Price Guide does not support the delivery of services within the Best Practice Guidelines – for instance:

Best Practice	Family Perceptions
○ To see children in natural settings	○ The cost of travel is seen as 'reducing' their 'therapy budget' and therefore, families opt for clinic-based models.
○ To appoint a Key Worker to work with a family	○ This cost is seen as 'reducing' their 'therapy budget' and families do not understand the value of Key Workers.
○ To support the family unit	○ Families are often reluctant to use funding on family support as it is seen as 'reducing' their 'therapy budget'.
○ To focus on 'capacity building'	○ Families lack an understanding of capacity building and prioritise therapeutic interventions solely for the children.

We acknowledge this has not been the intention of the NDIA in setting the Price Guide, but it is the unfortunate unintended consequences of the funding model as currently structured.

[4] Data accessed 21/2/2023 for Quarter 1 FY22/23 - https://data.ndis.gov.au/explore-data

C. MEDICAL MODEL

These challenges are underpinned by the 'medical model' which is often widely promoted by medical professionals like General Practitioners and Pediatricians. Families often come to services with the view that they only need 'therapy' and the more of it, the better.

Providers are also financially incentivised to deliver clinic-based models as they are cheaper to operate – running back-to-back sessions in an office is less expensive than the cost of paying staff to travel and upkeep the WH&S responsibilities that come with mobile workforces. Further, there is no regulation on how providers deliver services (e.g., natural settings or Key Worker – practices aligned to the Best Practice Guidelines) so there is no disincentive to operate in this way.

However, what we know from the research into the Best Practice Guidelines that the longer-term outcome of a purely clinic-based approach is less effective than the model within Best Practice Guidelines. Therefore, prioritising a clinic-based model leads to poorer outcomes for children, and families and therefore, more cost in the long run for the NDIA. It may also limit the gains of 'capacity building' for parents and children as it is difficult to fully practice skills in an artificial environment.

In the *NDIS Participant Outcome Executive Summary* in June 2021, **areas of concern revolved around declines in children attending mainstream classes** which is an issue for access and inclusion. Furthermore, in the *NDIS Family and Carer Outcomes Summary* from 2021, **deteriorations in social and community involvement were felt by families of children 0-14 years old.** Whilst this may not be a direct result of clinic-based models, it demonstrates that desired outcomes are not being achieved within the current system.

As there are significant wait lists in many areas, it could also be argued that there is in fact the now less choice and control for families, as families often must go to the first available provider, regardless of their service delivery model. This increases the likelihood that clinic-based models are being utilized as families have limited other choices.

Early childhood intervention services delivered in everyday and natural environments and through family-centered practices.

Clinical experiences

Office / Clinic Room

NOT USING BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

Impact is limited

O No inclusion.

O Poor ability to transfer learning to real life.

O Less opportunity to capacity build families.

O Less work as a Team.

Real life experiences with family and your community

School   Home   Family   Park

Childcare/ preschool   Shops

USING BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

Impact is wide reaching

O Supports children to be included.

O Capacity builds families.

O Work beside each other as a Team.
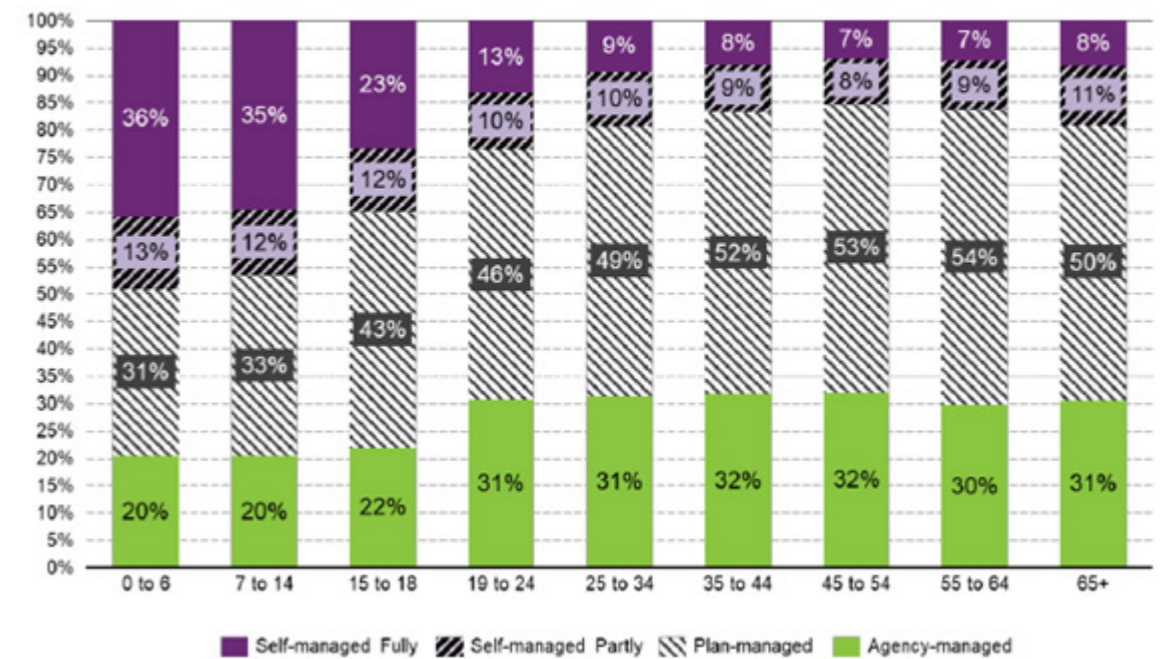
D. PRESCRIPTIVE PLANS

To add to the structural challenges of the price guide, we observe many cases where plans are no longer being designed to be flexible and responsive. Children's NDIA plans can be prescriptive about the number of Speech or Occupational therapy sessions the plan is costed to deliver. For instance, a plan may say, 'this is to deliver fortnightly speech.' Often, there is no costing done for travel (to enable natural settings) or Key Worker. Where this is observed, this is in direct opposition to the Best Practice Guidelines and results in less opportunities for inclusion supports and family capacity building.

E. LACK OF REGULATION

Unlike other childhood services (e.g., early childhood education services, out-of-home care services) which have regulation on quality of service, there is limited regulation in the quality of delivery of childhood services in the NDIA. And, there is no specific regulation to ensure alignment to the Best Practice Guidelines. Over 266,000 children were supported by the NDIA in Quarter 1 of FY'22/23 alone[5]. This is a significant number of children who have such limited safeguarding protections. We know how vulnerable children with disability are and this has been reinforced through our learnings from the Royal Commission into Institutional Child Sexual Abuse and child protection legislation in states and territories. It is deeply concerning that this space remains without adequate Child Safe protections.

Below is an extract from p. 44 of the *Early Childhood Early Intervention (ECEI) Implementation Reset – Project Consultation Report* published by the NDIA in November 2020. Please note, the table is copied as published and there is a typo regarding the date; we believe this should read 'as at 30 September 2020.'

EXHIBIT 14: DISTRIBUTION OF ACTIVE PARTICIPANTS BY METHOD OF FINANCIAL PLAN MANAGEMENT AND AGE GROUP AS AT 30 SEPTEMBER 2002 - NATIONAL

A two-thirds of NDIS participants in the age group of 0-14 are self-managed or plan managed. These families can and do access unregistered providers who are not audited against Quality and Safeguarding Standards. This creates risks including:

No guarantee that workers have appropriate NDIS Worker Checks or other relevant checks;

No guarantee that parents are aware to check or ask for this;

No assurance about the safeguarding practices of the provider.

Further, across all providers, registered and unregistered, there is no accreditation or review of whether providers are using Best Practice Guidelines to regulate quality outcomes.

There is no access for children under age 16 for mental illness

Mental health and wellbeing concerns in children and young people are at an all time high. The Department of Health in Victoria states that "14% of children and young people aged 4–17 years are affected by mental illness at some time" and that "75% of severe mental health concerns emerge by the age of 25."[6] Despite diagnoses of severe mental illness such as Schizophrenia, children under the age of 16 are not eligible for the NDIS which can delay early access and intervention. Whilst this may be seen as the role of Medicare and health-funding, there are gaps within this system as well, leaving vulnerable children and families without necessary supports.

Practical challenges with self-managed plans

As self-managed participants are paid in advance, there is opportunity for fraud within this system. Where there is misuse of funding by self-managed participants (e.g., spending money on non-NDIS related costs or overspending funds), this means that providers often provide services which are never fully paid as funds are exhausted. This is a challenge for the sustainability of the NDIS, as well as, the sustainability of providers.

Short Term

01 Address the lack of representation on the NDIS Board by recruiting with Directors who have personal or professional experience with early childhood services. As almost 50% of NDIS participants are children, the Board should proportionally reflect this in time – with a target to have 25% representation by 2024 and 50% by 2025.

02 Establish a children's portfolio within the NDIA to enable better oversight of this area.

03 Ensure NDIS plans support informed choice and control and reflect the Best Practice Guidelines, i.e. inclusion, natural environments and family capacity building are encouraged and funded.

04 Change the structure of the price guide to encourage use of funding within the Best Practice Guidelines. For example, one option would be to restructure the funding and Price Guide to provide separate 'buckets' of funding for:

- **Travel –** so families will not see this as reducing their direct services and will be encouraged to use this funding and access services in natural settings.
- **Key Workers** – so families will not see this as reducing their direct services and will be encouraged to use this funding.
- **Capacity Building** – so families will be encouraged to use this funding.
- **Family Supports** – so families will be able to access family therapy, support for siblings, capacity building, and even household support as required.

05 Require or incentivise families to use only registered providers for Early Childhood Early Intervention and Therapeutic Services to age 16.

06 Include audit on the delivery of services within the Best Practice Guidelines into existing NDIA registration system. This could include setting guidelines such as the % of sessions which have parent involvement and % of sessions in natural settings.

Medium Term

07 Develop an accreditation for Key Workers and make that a requirement of delivery of Key Worker services.

08 Require participants to be NDIA Managed for the first 2 years so they can build capacity through their engagement with existing registered providers who will serve a role in educating them through capacity building.

09 Commission research to develop Best Practice Guidelines that cover the ages of 8 to 16 years.

4. Workforce shortages of allied health workers and early childhood specialists

Of course, underpinning any strong system is a robust and healthy workforce.

The most recent S*tate of the Disability Sector Report 2022* by National Disability Services has cited allied health practitioners as the biggest skill shortage.[7]

This shortage is exacerbated by the overservicing in clinic models and limited use of the Key Worker model. The cost of employing graduates exceeds the current Price Guide which can mean lack of new graduates in the space, or those who engage new graduates may not ensure they are appropriately supervised.

Both issues lead to significant wait times for services, at a critical point of development for children.

In addition, early childhood specialists may come from a variety of professional training backgrounds. There are some unique challenges this presents including:

For Early Childhood Teachers, they are unable to obtain or maintain their NESA accreditation in this type of work which makes it difficult to attract those Teachers to this industry.

There is no classification within the *Educational Services (Teachers) Award* that recognises this community-type of work

[7] State of the Disability Sector Report 2022, Figure 10, page 31

Short Term

01 Expedited visa processes for allied health professions.

02 Review NESA requirements to account for this type of community work.

03 Review the *Educational Services (Teachers) Award* to account for this type of community work.

04 Provide financial subsidies to providers who employ new graduates for their first two (2) years of employment (similar to other approaches for trainees).

05 Invest in the development and delivery of Post Graduate accredited training in the Best Practice Guidelines for Early Childhood Early Intervention, including the Key Worker model. This has recently been an initiative for other areas such as:

a. Developmental Educators
b. Behaviour Support Practitioners
c. Play Therapists

06 Provide immediate training for staff of registered providers regarding delivery of early childhood early intervention in the Best Practice Guidelines. This training should be free for providers.

07 Development of clear workforce strategy for early intervention and allied health to complement other existing workforce strategies.

08 Provide incentives for study in the allied health and early childhood teaching professions.

Long Term

09 Work with universities and accrediting bodies to ensure the Best Practice Guidelines for Early Childhood Early Intervention, including the Key Worker model, are a requirement of curriculum.

Summary

Best Practice Challenges

Our overarching concern is that since the introduction of the NDIS, there are some unintended outcomes within the system structure that are not enabling best practice to be consistently achieved. Our concern is that by not operating within this evidence-based framework across all areas, optimal outcomes for children and families are not being fully realised. We hold genuine concern that this will lead to sustainability concerns for the NDIS and other service systems, as well as, mean the children and families are not afforded the best chance for success.

Below we have summarised the system challenges we have discussed above and how they relate to the Best Practice Guidelines.

QUALITY AREA 1: FAMILY

- Family-centred and strengths-based practice
- Culturally responsive practice

○ The system requires a diagnosis at multiple points. By doing so, it is not culturally sensitive. Diagnoses may also be problematic in the long run for children.

○ The structure of Medicare and NDIA funding does not enable family-support.

○ Early access points in the community are not funded to provide local support to families in either a preventative or responsive way.

○ Early supports are often focussed on the child, not the family unit as a whole.

QUALITY AREA 2: INCLUSION

- Inclusive participatory practice
- Engaging the child in natural environments

○ The structure of funding in early childhood education settings does not enable inclusion.

○ Children under 16 with mental illness are excluded from the NDIA.

○ The structure of Medicare and NDIA funding does not enable service delivery in natural settings.

○ The medical model promoted by health professionals is often clinic-based (rather than promoting support in natural settings).

QUALITY AREA 3: TEAMWORK

- Collaborative teamwork practice
- Capacity-building

○ The structure of Medicare and NDIS funding does not enable or encourage use of a Key Worker or collaboration with other professionals as part of the 'Team Around the Child.'

○ The structure of Medicare and NDIS funding does not enable or encourage families to participate in 'capacity-building.'

○ The medical model promoted by health professionals is often clinic-based and does not promote use of Key Worker.

○ Collaboration between mainstream and funded providers is not an expectation that is enforced.

QUALITY AREA 4: UNIVERSAL PRINCIPLES

- Evidence base, standards, accountability and practice
- Outcome-based approach

○ The medical model promoted by health professionals is often clinic-based and does not promote use of Key Worker.

○ The structure of the Medicare and NDIS funding unintentionally promotes a 'more is better' approach, rather than focuses on outcomes.

○ There is limited regulation on use of evidence-based practices, including the Best Practice Guidelines, within the NDIS.

○ There are workforce shortages and a lack of support to enable training of new graduates, which limit capacity to achieve objectives.

○ Formal recognition of early childhood intervention is limited in the Early Childhood Teaching profession – this critical discipline requires recognition.

Outcomes Challenges

In addition to the concerns listed above, there are additional systemic challenges within the systems which limit the ability of desired outcomes to be achieved. These are summarized below:

- Lack of prevention focus within services generally.

- Lack of independence between the ECI Partners and the NDIA can be a barrier to access.

- Lack of clarity between state-funded services and the NDIA regarding responsibility for assessments, supports and interventions.

- Lack of early childhood representation within the NDIA and its Board limits full and comprehensive undersanding, and investment in, early intervention.

- Fraud within the NDIS, particularly for some self-managed participants, threatens sustainability of the NDIS.

In Conclusion

We believe that policy and funding changes can go a long way to resolving these concerns and realising the desired outcomes for children and families and the sustainability of the systems that support them.

We are keen to engage in consultation to hear the perspectives of others, including participants, and work together to co-design robust solutions that will enable positive outcomes for children and families, delivery of services within Best Practice Guidelines, and ensure sustainability of service systems.

We present these possible solutions as a starting point for discussion and consideration and we would be grateful for the opportunity to meet to discuss in more detail.

We thank you for your time in reviewing this paper and look forward to further discussion.

Appendix A: Case Studies

The following case studies based on actual experiences help to illustrate the challenges of the current system.

1.   Early Access Points

CASE STUDY 1 – PRESCHOOL HIGH LEARNING SUPPORT NEEDS FUNDING

One provider operates community preschools in a multicultural area. They regularly have children who attend who are not eligible for the NDIS due to their visa status. The provider attempts to accommodate these children by accessing High Learning Support Needs funding; however, the low funding levels mean that staffing levels do not fully support the children's needs, especially behavioural needs. And, there are no apparent access pathways to access early intervention for these children. For these children, their behavioural symptoms can lead to more difficult social relationships and inclusion within the centre.

It can also strain workforce and limit capacity for a quality learning environment.

THIS CASE STUDY HIGHLIGHTS:

01 The need for revised guidelines and increased funding for inclusion supports;

02 The need for early intervention services to be funded for children who are not eligible for the NDIA.

2) Formal Services to Enable Early Intervention

CASE STUDY 2 – ACCESS EXPERIENCE FROM A PROVIDER'S PERSPECTIVE PRE-NDIS AND POST-NDIS

PRE-NDIS ACCESS TO EARLY INTERVENTION

3 STEPS AND WEEKS TO SUPPORT

01

Provider's staff would be called by local regional Hospital to meet parents at birth and do intake for a child and immediately support the family with information in their local community

OR

01

Parent would ring up or walk in the door

02 Meet face to face with a family support person and early childhood intervention professional and reception staff who are experienced in working with families and children with disability

03 • Guided by same person at that time through Government, organisation and community services and supports that are relevant and available in their community.

POST NDIS ACCESS TO EARLY INTERVENTION

9 STEPS AND UP 12 MONTHS TO SUPPORT (HOW THINGS ARE WORKING IN REALITY)

01

Hospital in a regional area will tell family to contact ECI partner on birth or discharge and give them a 1800 number for a Sydney based ECI partner

OR

01

Parent may ring us concerned that they or someone has identified that their child may have a developmental concerns and they want to know how they can 'access the NDIS' and we let them know that they need to ring the ECI partner

02 Family will ring the ECI Partner in the Community and do a referral over the phone with basic details. They are told someone will be in touch with them within 3 months

03 Family will receive a phone call from the ECEI partner and they will take more details and either do phone consult to determine if they meet access or a face to face visit

• Provided with emotional support and information about best practice in their local place-based setting and supports connections within their community

• Children would start, often within weeks, in services which were family centred, local and grounded in evidence-based practice. Supported by the same people through paediatrician, health and education

• Ongoing parent support from other parents and specialised early intervention professionals and family practitioners Ongoing individualised inclusion advocacy, strategies and connections with community and community groups, for people who know both the family and the area's local services well.

04 Family may (are often) required to get evidence and documentation for access

05 Families ring local paediatricians, speech pathologists, psychologists for diagnosis or report but wait 6 months or can't afford the payment for private consultations

06 Take the reports back to the ECI Partner who will then determine if the child meets access or not and if so, they will have a planning meeting. If not, they will go on long waitlists for community health support, for private practice or often not receive any support

07 ECI partner submits application and family waits, potentially a few months to meet access

08 Family gets a plan back with money broken into various buckets which they need to interpret – what they can use it for, who they can use it with and how they are paid.

09 Family contacts service providers and is told they are on a waitlist for early intervention services for sometimes up to 3-12 months.

CASE STUDY 3 – BABIES ACCESSING COMMUNITY HEALTH

A family had a baby in 2021 and as per usual protocols, followed up with their local community health service's child and family health nurses. The child was not thriving and dropped to the 10th percentile with weight (born in the 90th percentile) and 3rd percentile with head circumference (born in the 36th percentile) within approximately six weeks of birth. The child and family health nurses stopped seeing the baby at three months despite these concerns. The child and family health nurses communicated they had no capacity to assist the family and that due to the 'large number of births' they could not see the family even at regular checkpoints that would typically be expected. As a result, the family sought support from a private paedatrician who moved the family to weekly monitoring of the child until progress was seen and maintained. There was no follow up and remains no follow up from the child and family health nurses to this day. The child is now 21 months old.

With this same case, due to financial strain, the mother returned to work at six weeks post-birth. The father was the primary carer through this difficult period of growth concerns. At the final appointment with the child and family health nurses, the nurse enquired how mum was doing. The nurse did a depression inventory for the mum. Mum explained it had been difficult for her husband as well who is at home fully time with the child. The nurse stated that there was no need to have further discussion about dad's wellbeing or do any screening for dad as 'the system does not require this' (referring the computer system which prompted the depression inventory for mum).

THIS CASE STUDY HIGHLIGHTS:

01 How children can 'fall through the gaps' (had this family not connected with a local paedatrician, it is unclear what would have happened);

02 How the approach is not always holistically family-centred;

03 How strained the resources are in many community health settings that they do not have capacity for ongoing involvement.

CASE STUDY 4 – ACCESS CHALLENGES WITH ECI PARTNER ROLE

A family from Samoa's child was experiencing speech delays. From 18 months, the child was not speaking, and the wider family actively encouraged them to speak to their doctor and increase social opportunities for the child. After a year of no action, they were finally convinced to make contact with their local ECI Partner. When they made the initial call, the ECEI Partner told them that they could not help unless the family went to the GP and got a referral for five Medicare sessions. They were told that if they had the Medicare sessions, then the ECEI Partner could deliver therapies. Unfortunately, not trusting the health system, the family did not pursue this, and delays continued.

After another six months of pestering by the family and assurance from a family member that they do not need a Medicare referral, the family called the ECI Partner again. This time it was suggested that they go attend local playgroups. No specific details were provided about where to find or access these playgroups and no invitation for assessment was made. The child at this point was three years old and had a vocabulary of three (3) words and significant behavioural issues.

The family, who was already hesitant to access the ECI Partners due to cultural stigmas about formal systems, now is unwilling to go back to the ECI Partners given the lack of help experienced in their first two interactions. This child at age 4 ½ has now started preschool and the family hopes that they may receive some support in this setting; however, we are aware of the limitations of funding in these settings.

THIS CASE STUDY HIGHLIGHTS:

01 The challenges of having only one ECEI Partner per region;

02 The challenges of having ECEI Partners which also deliver therapeutic services;

03 The challenges for multicultural families to access services;

04 The lack of local connections for many ECEI Partners;

05 How children can 'fall through the gaps.'

CASE STUDY 5 – INEQUITY OF ACCESS TO ECI PARTNERS

We have seen many situations through our relationships with Community Health where their clients have been referred to ECI Partners, only to be denied access or sent back to community health to support, these children have met requirements for access due to the fact that they have had an actual diagnosis of disability, not to mention the others that have had GDD (Global Developmental Delay). These families were not even sent through to the Short Term Early Intervention Program to connect with other mainstreams supports, just told they were unable to access the ECI Partners.

THIS CASE STUDY HIGHLIGHTS:

01 The inconsistent approach many families experience with trying to seek access;

02 The lack of clear guidelines between community health and the NDIA regarding supports;

03 How families can fall through the gaps.

3) National Disability Insurance Scheme and Funded Services

CASE STUDY 6 – PROVIDERS NOT ALIGNED TO BEST PRACTICE

A community-based provider of Early Childhood Intervention (ECI) for 30 years, has been working in the Key Worker model since 2010. They have been referring children and their families to a new psychology service in their area for 3 years under the model of collaboration. In the past three (3) months the psychology service has grown rapidly and begun recruiting workers to provide transdisciplinary services, changing the relationship with the ECI provider. The psychologist has communicated in person and via email:

• they do not believe in the Key Worker model;

• that until their arrival children have received inappropriate services;

• families will be 'educated' as to the most appropriate services for participants (this means they are using their influence to encourage families to end supports with the ECI provider and engage with the psychology service exclusively);

• will not respond to communication from ECI provider about shared participants;

• will only refer to external Allied Health professionals within their circle;

• will continue to claim for assessments and diagnoses under the NDIS;

• will adjust a diagnosis if more funding is necessary;

• will push for caregivers to undertake plan reviews if funding does not meet their requirements for claiming for assessments.

This situation is extremely damaging to the morale and workloads of staff working both directly with families and in plan management. In some cases, staff have experienced direct intimidation from this psychologist and families have left the ECI provider, citing pressure and the belief they are going to get the best supports for their child.

Preschools and school are also being intimidated by this psychologist practice.

THIS CASE STUDY HIGHLIGHTS:

01 The varied use and understanding of the Best Practice Guidelines;

02 The lack of collaboration experienced with some allied health providers;

03 The potential for providers to use funding for diagnosis and assessment which is not the intention of the NDIS funding;

04 The propensity to diagnose (which may have negative long term outcomes) purely for the sake of funding.

CASE STUDY 7 – DUTY OF CARE AND PRACTICAL CHALLENGES

One organisation was approached by a family to apply for a review so she could be "Self Managed", we advised that we didn't feel her current situation left her with the capacity to self manage, we went to review and advised the ECEI partner in the community about our concerns, they advised that they under "choice and control" had no grounds to withhold the request and switched the family to Self-Management.

Within 48 hrs the parent accessed the full amount of the child's funds and used them to post bail, leaving the child with no supports moving forward and no review process that would support the child.

THIS CASE STUDY HIGHLIGHTS:

01 The challenges with no regulation and oversight of self management of funds;

02 The potential for system fraud that puts children's wellbeing at risk;

03 No recognition of the responsibility being placed on parents and risk it puts them in if there are vulnerabilities.

CASE STUDY 8 – INCONSISTENCY IN PLANS AND FUNDING

One organisation has two (2) children with the same "diagnosis," working with the same Key Worker (over 25 years experience). These two children have two very different scenarios.

The first child has a strong formal and informal support network, access to an early childhood education setting five days a week, and engagement in community and extra curricular activities. Funding provided for over $100,000.

The second child is highly at risk of homelessness, the primary caregiver is the only formal support, access to only two days early childhood education, primary caregiver parks at childcare centre all day as she is unable to afford the fuel to drive in and out for pick up and drop off, and has very limited informal supports. This child's funding package provided just under $26,000.

THIS CASE STUDY HIGHLIGHTS:

01 The inconsistency in planning and access to funding;

02 The lack of consideration of family needs, despite the importance of this under the Best Practice Guidelines.

CASE STUDY 9 – PRICE GUIDE NOT BEING FOLLOWED

We have a registered provider in the area who has just "changed their billing structure" to $290/session (exceeding the price guide limits of $193.99 per session). They sell a package at this rate that includes 10 x 45 mins face-to-face the rest of the session is in non face-to-face "direct supports" consisting of research, session planning, notes, case conferencing, client care and outcomes reporting/session. In addition, the package includes eight (8) hours for end of plan review reports. They have been reported to both ECI Partner and LAC who have reportedly advised them they "can't charge that amount" but it has not stopped them and they are continuing to sell this model as "Best Practice."

It was advised in further discussion with the therapy provider founder and their lead practitioner was that "this new model allows us to be outcomes based, up until now (since 2014) there has been no accountability or requirement for us to be outcome based focus." An outcomes focus is one of the key principles of the Best Practice Guidelines.

THIS CASE STUDY HIGHLIGHTS:

01 The lack of oversight of providers to ensure they are following Best Practice Guidelines;

02 The opportunity for providers to overcharge participants.

APPENDIX B - Participating Organisations (Alphabetical Order)

Organisation	Location	Number of children support annually in early intervention (NDIS under 7s)	Number of children/ young people supported annually (through all services)	Representative
BRIDGES FOR LEARNING	NSW – Southern Highlands	53	125	Kathleen Hornery
EARLY CONNECTIONS	NSW – Coffs Harbour & Bellingen Shire	150	217	Caryn Maher
EARLYED (EARLY EDUCATION INC.)	NSW – Western, Northern and Nepean areas. Nationally online.	320	1200	Kerry Dominish
KOORANA CHILD & FAMILY SERVICES LTD	NSW – Sydney, Sutherland Shire, and South Western Sydney	150	1500	Morgan A. Fitzpatrick
MUDDY PUDDLES	NSW – Batemans Bay	66	202	Cate McMath
NOAH'S INCLUSION SERVICES	NSW – Illawarra/ Shoalhaven	370	1900	Alice Lans
NOAH'S ARK INC	VIC – Metro and Regional - ACT NSW – Albury/Wodonga	53	125	John Forster
PLAYABILITY	NSW - Bega	78	142	Geoff Johnston
PLUMTREE	NSW – Sydney Inner West	800	800	Sylvana Mahmic
ROYAL FAR WEST	NSW – Far West	469	1656	Fiona Phipps
SDN CHILDREN'S SERVICES	NSW – Sydney region	160	4803	Kay Turner Christine Zuvela
SHAPING OUTCOMES	NSW – Gold Coast - Grafton	350	450	Colin Usher
THE INFANTS' HOME CHILD AND FAMILY SERVICES	NSW – Sydney Inner West	0	2500	Elizabeth Robinson
TREEHOUSE	NSW - Queanbeyan	142	278	Karen Mills

APPENDIX C - References

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Department of Social Services Summary report: Peer support for families with young children with disability and developmental concerns

13 July 2022

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Summary report

Good social supports are critical to the wellbeing of parents/carers, their ability to parent responsively and to successfully navigate the health, education and disability systems that support their children.

> *Just as the core thing that a child needs is attachment, bonding, security, people who are totally committed to them and respond appropriately to them, someone needs to be able to give to the family. Someone has to be crazy about that kid, and someone has to be crazy about their caregiver. The quality of your parenting will be affected by your support network. The majority of people have people who can share the load, and provide them with emotional support. If they don't and they are resourceful enough they find them, through mothers' groups or whatever. However, that is not a system that works consistently. Some people don't have support and this is where government can step in.* Academic/researcher

Australia's Disability Strategy 2021-2031 (the Strategy) is Australia's national disability policy framework. The *Early Childhood Targeted Action Plan* (EC TAP) sits under the strategy and focuses on children from infancy to school age with disability or developmental concerns, their families, and carers.

This research study was commissioned by the Department of Social Services to support implementation of Australian Government EC TAP Action 3.1: *Analyse existing community support models of peer networks, to identify inclusive, innovative and adaptable approaches and to support participation of all parents and carers. This includes, but is not limited to support models tailored for rural and remote locations, Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and carers*. The methodology comprised:

- A review of the literature
- Qualitative and quantitative fieldwork with parents/carers of young children with disability and developmental concerns, including 10 small group discussions and 16 in-depth interviews, and an n=323 online survey
- Qualitative fieldwork with people working in peer support, the disability and early childhood sectors and in research and policy roles, including 35 interviews and 7 online workshops.

Fieldwork was conducted in June and July 2022. This report summarises key findings and recommendations.

Key findings

Mapping peer support options available to parents

The literature review found that peer and social supports have increasingly been adopted across the health and community service sectors as a means of increasing social connectivity, reducing stress, and addressing unequal power relations between professionals and individuals. Research shows that beneficiaries value peer support and describe benefits that include increased confidence, a sense of belonging and a positive sense of community. Peer support has also been found to increase families'

capacity and skill development, including how to access information and services and advocate when their needs are not being met.[1]

The review identified three categories of peer support (1:1, group, and online) which were then validated through the primary research. The peer support categories, and models of support under those categories are:

- 1:1: Telephone information and lines; support to navigate systems
- Group: Short-term information and capacity building; ongoing parent support groups; supported playgroups; events/activities
- Online: Websites; online communities/Facebook; podcasts; apps.

The review found little evidence for how different peer support categories or models contribute to outcomes for families, including with respect to attracting and retaining diverse families and families with more complex needs. The primary research also explored what parents/carers of young children with disability and developmental concerns value with respect to peer support. It found that the benefits of peer support are not tied to particular delivery modes or programs, but rather linked to opportunities for emotional support, insider insights and information, system navigation and social connection. These benefits can equally be derived from 1:1 or group, online or in person, one off or prolonged engagements – depending on the design of the program and the preferences and needs of parents/carers.

Limitations/Gaps

Whilst comprehensive, the current peer support system for families with young children with disability and developmental concerns is fragmented and lacks connections to the broader early childhood service sector. Substantial gaps exist with respect to providing 1:1 and online supports, and supports for:

- families who are pre-diagnosis, who are not connected to the National Disability Insurance Scheme (NDIS), and who are waiting to access services
- families navigating access to the NDIS and education systems
- fathers and male carers
- First Nations and culturally and linguistically diverse families, including migrants on temporary visas
- families experiencing significant life challenges
- families living outside metropolitan areas.

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[1](Hammarberg et al., 2014) (Meltzer et al., 2020)

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However, there appear to be broader issues with the reach of peer support programs, and barriers to engagement. In addition to gaps for specific population groups, there are also issues of loneliness and isolation at the population level. A significant proportion of parents/carers of young children with disability and developmental concerns do not have access to good emotional supports, or the opportunity to talk about their child's needs and strategies for addressing these. Some described a vicious circle where feelings of anxiety or anger put up further barriers to engaging with other people in their lives.

To illustrate, of the parents/carers surveyed:

- 58% would like more connection with other families with children like theirs but don't know where to find this
- 66% have someone they can talk to when they have questions about their child's needs
- 60% have someone to workshop problems and solutions with
- 48% say that they often can't get help when they need it
- 31% don't have anyone they can confide in
- 29% have no one to lean on in times of trouble.

I feel like I've no one I can turn to if I have a problem, no one to delegate things that need to be done so I feel overwhelmed and under stress everyday. I feel like it makes me less patient when raising my child, and I fear this will have an impact on them as they develop. Parent/carer

Opportunities

Our analysis has suggested that there is an opportunity to better meet the needs of parents/carers of young children with disability and developmental concerns through providing more consistent opportunities to engage in peer support, and tailoring opportunities to better meet the needs of families. However, achieving this would require changes to funding arrangements, how programs are delivered, and significantly more coordination and cooperation between peer support delivery agents than currently exists. The following design issues will also need to be addressed.

No one peer support model will meet the needs of all

Parents/carers with young children with disability and developmental concerns express a preference for a variety of peer support models (group/1:1, face-to-face/online/telephone/ text, ad hoc or ongoing). They note that these preferences might change over time and with situational need. In addition, many families may not be looking to *formal programs* for emotional connection, and may prefer peer supports to come through their natural networks. These varied preferences emphasise the need to offer a range of peer support options, and that there is no 'one size fits all' approach to meeting needs – rather, a peer support system is required.

Effective peer support design requires co-design and deep listening

Whilst the different peer support models have strengths and weaknesses, it is not possible to predict what options will be most appropriate for any given population cohort. To illustrate, some culturally and linguistically diverse and First Nations parents/carers in this research study preferred peer support options that sat within their cultural community, whilst others wanted to engage with families in their geographic community. Co-design of peer support, and deep listening, are required to determine what will best meet the needs of individual parents/carers – by definition, this involves place-based supports rather than a strict model imposed at the national level. Local communities and organisations are best placed to support translation of good peer support practice in a meaningful way.

Low awareness of the available peer support options and lack of interest in 'reaching in'

Many parents/carers of young children with disability and developmental concerns are not aware of what peer support is available or would not reach in if they were. The benefits of peer support aren't immediately obvious to parents/carers, who tend to put their own emotional support needs last. This again emphasises the need to work through existing relationships of trust – and through local communities and organisations.

A broader role for peer support than 'programs'

The literature specific to peer support for families with children with disability and developmental concerns typically focuses on programs. This emphasis is reflected in the service system. Other sectors – notably mental health – use the concept of lived experience to frame the role of personal experience. The benefit of this frame is that it helps shape a broader role for lived experience – where people with lived experience are central to the design and delivery of the overall disability sector, rather than merely program recipients or facilitators.

It is also possible to think about the role of peer support for parents/carers beyond the disability sector. Moore, for example, argues that the starting point for designing peer support interventions should be mapping families' broader social ecosystems, and that these may encompass a variety of service sectors – not just disability.[2] This lens considers connection to peers and the broader community as a social determinant of child and family wellbeing, and prioritises natural networks, including existing child and family services connections. In this context, professionals could note that the role of peer support as an enabler of good parenting is not limited to parents with young children with disability and developmental concerns – and that many families would benefit from more support with respect to parenting. This includes parents of children with disability and developmental concerns pre-diagnosis.

Monitoring and evaluation

As mentioned, there is little evidence for the effectiveness of peer support interventions in the literature and a need to think about how to more consistently measure the success of peer support. Developing a national monitoring and evaluation framework would provide a basis for more consistent measurement.

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[2]Personal communication as part of an interview for this study.

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A consistent, coordinated peer support system

This research study has suggested the need for a tiered approach to developing peer support interventions. This acknowledges that not all families require additional intervention, and for those that do, different levels of support are likely to be appropriate. The table below illustrates this continuum of support.

TABLE 1. TIERS OF PEER SUPPORT

	Family descriptor	Support needs
Tier 1	Families with children with disability and developmental concerns	Additional support required with respect to disability/developmental concerns: e.g. system navigation, goal setting and supporting children in natural environments
Tier 2	As above, and with poor social connection/means to create connections	As above May also need social and emotional supports May need support to engage
Tier 3	As above, and experiencing serious life challenges or cultural barriers to engagement	Disability peer services layered through existing (place-based and culturally specific) service delivery

The requirements for a peer support system are outlined in more detail in the table overleaf.

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TABLE 2. REQUIREMENTS OF A PEER SUPPORT SYSTEM: KEY FEATURES OF A WELL-FUNCTIONING AND HIGHLY VALUED PEER SUPPORT MODEL

Identified needs	Why this is needed	What this looks like	Role of peer support
A 'way in' to peer support	There is a need to create ways for parents/carers to understand the peer support options 'menu'	Multi-dimensional universal touchpoints (e.g. baby bag, mothers' groups) as well as soft entry points (e.g. warm referrals from early childhood and community services) and social media advertising to interrupt online searches	Create an understanding of the full menu Community Champions as connectors
Responding to a diagnosis	Parents/carers tell us that initial diagnosis can be devastating, and they don't always get good support at this time	Universal peer support offered at the time of diagnosis that is closely connected to health system This is a 'sitting with' service that doesn't demand anything of families – may be face-to-face or linkage service	Support for distress and providing a sense of hope and optimism (parents/carers and children can lead thriving lives post-diagnosis) Permission to 'feel as you feel' through empathy/ understanding
1:1 system navigation	Whilst there are many group offerings supporting system navigation, there is little 1:1 peer support at key transition points	A universal 1:1 system navigation service	Peer workers can provide advice on navigation with a 'ground up' perspective, as well as emotional support
Family goal setting	Goal setting that promotes family centred participation can support engagement with the NDIS	Peer-led positive vision planning is encouraged before engaging with the NDIS planning process	As per above
Connection with peers	Whilst this isn't often a primary driver for parents/carers to engage, the consensus amongst those who have engaged with peer support is that it is much needed	Multifaceted programs to meet different needs: e.g. low-pressure opportunities to trial support options; socialisation for children; action focus for men and so on….	Peer workers as per above Peers as participants (parents/carers, children, siblings, extended family)
Information, advice and skills building	A key driver for parents/carers to engage	Meeting a variety of parent needs via universal and more tailored approaches (e.g. from websites to group supports)	Peer workers and participants as per above
Mainstream inclusion	The mainstream (e.g. service system and other families) is not genuinely accessible and inclusive	Social marketing campaigns targeted to families, capacity building for the early childhood, community and recreation sector workforces	Encouraging families in the general community to be more inclusive to make natural peer support a more viable option
A safe space	Whilst mainstream services/the general public can be judgemental or not a good fit developmentally, there can be a need for safe spaces where families with young children with disability and developmental concerns are naturally included	Supported playgroups, recreation opportunities, including family activities/days out specifically for those with children with disability/developmental concerns	Peer workers and participants as per above

Options for short-term funding

The following section outlines discrete actions that could be undertaken under EC TAP Action 3.2. *Pilot a peer-led support program. Develop and trial innovative new approaches for peer-led supports tailored for particular cohorts, co-designed by parents and carers of children with disability or developmental concerns, and people with disability.*

This evidence base has not suggested that there is one specific model that should be implemented. Instead, the need is to learn from and build on existing good work and incorporate the design principles outlined above.

Option 1. Promote peer support options – mainstream workforce capability building

Key issue	There is an opportunity to build the capacity of the early childhood workforce to make warm referrals to peer support.
Role of peer support	Warm referral to peer support.
Example activity	Include a focus on peer support in workforce capacity building programs (existing and new).

Option 2. Fill system gaps via peer support

Key issue	Families have emotional needs that are not being met through the current service system. This includes through key transitions, such as waiting for a diagnosis or access to services. Service gaps are likely to be particularly acute or exacerbated in rural and remote areas.
Role of peer support	Where there are thin markets or service gaps, there appears to be an opportunity to build capacity in the community to meet families' practical and emotional support needs.
Example activity	An example workshopped with stakeholders in the study is to recruit and train paid peer workers in rural/regional/remote areas who would be based in local hubs (e.g. neighbourhood houses, child and family hubs) to create social opportunities and support goal setting and development strategies.

Option 3. Support equitable access

Key issue	A number of useful peer support options have good coverage in some jurisdictions but not others.
Role of peer support	Differs depending on the nature of the peer support activity.
Example activity	An example is 1:1 system navigation, which is currently offered in some but not all jurisdictions.

Option 4. Layer service delivery

Key issue	Families with multiple challenges and in culturally specific settings will likely benefit from layering supports that are usually offered through disability-specific peer support programs.
Role of peer support	Varies depending on the nature of the peer support activity.
Example activity	A way to do this would be to fund existing programs that use peer support or have strong community connections or place-based approaches. Ideally these

Key issue	Families with multiple challenges and in culturally specific settings will likely benefit from layering supports that are usually offered through disability-specific peer support programs.
	programs would be mentored and supported by disability-specific peer support organisations.

Future considerations

Option 5. Promote peer support options – communication campaign

Key issue	A key barrier to families accessing peer support programs is that parents/carers simply do not realise these programs exist.
Role of peer support	Promotion of peer support options.
Example activity	A multifaceted government campaign directly communicating the availability of peer support options to parents/carers.

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